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LONG-TERM HEALTH CARE

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

FEBRUARY 24, 1987

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LONG-TERM HEALTH CARE

TUESDAY, FEBRUARY 24, 1987

U.S. SENATE,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON FINANCE,
Washington, DC.

The committee was convened, pursuant to notice, at 10:00 a.m. in Room SD-215, Dirksen Senate Office Building, the Honorable George J. Mitchell (chairman) presiding.

Present: Senators Mitchell, Bradley, Packwood, and Chafee.

[The press release announcing the hearing and the prepared statement of Senators Chafee and Heinz and a background paper prepared by the Congressional Research Service follow:]

[Press Release No. H-17]

FINANCE SUBCOMMITTEE ON HEALTH TO HOLD HEARINGS ON LONG-TERM CARE

Washington, D.C.—Sentor George J. Mitchell (D., Me.), Chairman, announced today that the Subcommittee on Health of the Senate Finance Committee will hold a hearing on Tuesday, February 24, 1987 to examine the issue of long-term care. This hearing will be the first in a series of hearings on long-term care, and will be an overview of the need for long-term care, types of long-term care services available, current programs for providing and financing long-term care, and problems with access to services.

Senator Mitchell stated that the Subcommittee wants to examine all aspects of long-term care provided in hospitals, nursing homes, in the home, and in other settings, including demonstration projects and innovative approaches to providing services.

The hearing will begin at 10:00 A.M. on Tuesday, February 24, 1987 in Room SD-215 of the Dirksen Senate Office Building.

Additional hearings will be announced later which will focus on particular aspects of long-term care such as quality assurance and financing, including private insurance.

STATEMENT BY
SENATOR JOHN H. CHAFEE
AT
SUBCOMMITTEE ON HEALTH
HEARING ON
LONG TERM CARE FOR THE ELDERLY
FEBRUARY 24, 1987

MR. CHAIRMAN, THE HEARING WE ARE HAVING TODAY IS LONG OVERDUE. THERE HAS BEEN A GREAT DEAL OF DISCUSSION LATELY ON THE ISSUE OF CATASTROPHIC HEALTH CARE. IN MY OPINION, ANY HEALTH RELATED CRISIS WHICH HAS THE POTENTIAL OF FORCING AN INDIVIDUAL OR FAMILY INTO OR NEAR POVERTY IS CATASTROPHIC. PROBABLY THE MOST CATASTROPHIC HEALTH CARE EXPENSES AN ELDERLY INDIVIDUAL FACES TODAY ARE THOSE RELATING TO A CHRONIC ILLNESS THAT REQUIRES SOME TYPE OF LONG TERM CARE.

WHILE IT IS TRUE THAT BETWEEN THREE AND FOUR PERCENT OF MEDICARE BENEFICIARIES FACE OUT-OF-POCKET EXPENSES OF OVER $2,000 EACH YEAR, ABOUT FIVE PERCENT OF ALL ELDERLY INDIVIDUALS ARE IN NURSING HOMES AT ANY ONE POINT IN TIME AND THE LIFETIME RISK OF ENTERING A NURSING HOME IS ABOUT TWENTY PERCENT. THE AVERAGE COST OF ONE YEAR IN A NURSING HOME IS APPROXIMATELY $22,000.

FOR MOST OF THE ELDERLY, THE RISK OF NEEDING LONG TERM CARE AND ENTERING A NURSING HOME IS THEIR MOST PARALYZING FEAR. THEY HAVE GOOD REASON TO BE CONCERNED. ONE-HALF OF ALL NURSING HOME PAYMENTS ARE OUT-OF-POCKET EXPENDITURES BY THE ELDERLY AND ALMOST ALL THE REST ARE PAID BY THE MEDICAID PROGRAM. APPROXIMATELY ONE-HALF OF ALL MEDICAID RECIPIENTS IN NURSING HOMES WERE NOT INITIALLY POOR, BUT SPENT THEIR INCOME AND RESOURCES ON LONG TERM CARE BEFORE BECOMING ELIGIBLE FOR MEDICAID.

NO ELDERLY INDIVIDUAL OR COUPLE SHOULD BE FORCED INTO POVERTY BEFORE ASSISTANCE WILL BE PROVIDED FOR LONG TERM CARE FOR A CHRONIC ILLNESS OR DEBILITATING CONDITION LIKE ALZHEIMER'S DISEASE. I AM CO-SPONSORING LEGISLATION WITH SENATOR MITCHELL DESIGNED TO ADDRESS THE ISSUE OF SPOUSAL IMPOVERISHMENT IN THESE SITUATIONS; HOWEVER, MUCH MORE MUST BE DONE.

ANY CATASTROPHIC PROPOSAL, IF IT IS TO TRULY ADDRESS THE ISSUE OF CATASTROPHIC HEALTH CARE EXPENSES, MUST INCLUDE PROTECTION AGAINST THE IMPOVERISHMENT OF THE ELDERLY AS A RESULT OF THE COST OF LONG TERM CARE AND IT MUST ADDRESS THE GROWING NEED FOR ASSISTANCE IN THE HOME.

I LOOK FORWARD TO HEARING THE TESTIMONY PRESENTED TODAY. I HOPE THAT SOME OF THE GROUPS REPRESENTING THE ELDERLY WILL SUGGEST

FAR REACHING SOLUTIONS TO THE PROBLEMS WE FACE -- PROBLEMS WHICH WILL CONTINUE TO GROW AS THE POPULATION OVER 65 INCREASES.

Opening Statement

of

SENATOR JOHN HEINZ

U.S. Senate Finance Committee

Subcommittee on Health

Hearing on Long Term Care

February 24, 1987

Mr. Chairman, I commend you for calling this hearing on what is the most devastating problem facing older Americans -- the cost of a long term, chronic illness. It is especially appropriate that you have convened this hearing now in light of President Reagan's recent endorsement of Secretary Bowen's catastrophic health care proposal. For all of its strengths, the Bowen proposal falls far short of the mark when it comes to coverage for chronic, long term care.

As chairman of the Senate Aging Committee for the past six years, I have heard testimony from scores of families with heartbreaking stories of financial ruin and hardship caused by a loved one who had an extended nursing home stay. The crushing costs of nursing home care -- $50,000 a year or more -- is a catastrophe in itself. With these costs, it is not surprising that half of all nursing home residents are impoverished, relying on Medicaid to pay their bills.

The real catastrophe is the nearly complete lack of protection for most middle-class Americans. Last year, Americans spent $39 billion on long term care, averaging more than $22,000 per patient. Half of this cost was paid out-of-pocket by the elderly and their families. Only 1 percent was paid by private insurance. The remainder was paid by Medicaid, protecting those who are poor or who became poor after entering a nursing home.

Medicare does not cover chronic, long term care. Nonetheless, most Americans believe Medicare will take care of them when they enter a nursing home. This information gap could be at the heart of this nation's inability to solve the long term care financing problem; most Americans don't realize it is a problem until it's too late.

Solving this problem will not be easy. A step in the right direction is the bill you, Senator Mitchell, will be introducing soon, and on which I am a cosponsor, to prevent the impoverishment of spouses of nursing home residents who are on Medicaid. Improving services for Alzheimers patients will also help. Likewise, expanding home health benefits and improving the Medicare skilled nursing benefit will relieve some of the pressure on families who now provide two-thirds of the care for chronically ill elderly in this nation.

A true solution to the problem, however, will require a comprehensive approach, one that ensures access to services along the entire continuum of care -- from home health to nursing homes. Such a solution must be affordable, which means we, the federal government, must play a role. Private insurance can be a partial solution, but its cost will prevent most Americans from purchasing policies.

With the nursing home population facing explosive growth in the future -- from 1.5 million today to 3 million in 2020 and nearly 5 million in 2040 -- we must act now to develop workable financing for long term care. This hearing will help to move us toward that goal.

I look forward to the fine set of witnesses appearing here today. I especially want to welcome a constituent of mine, Dr. Stanley Brody, a renowned gerontologist from the University of Pennsylvania.

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FINANCING AND DELIVERY OF LONG-TERM CARE SERVICES FOR THE ELDERLY

Prepared for the use of the
Senate Committee on Finance

Carol O'Shaughnessy
Richard Price
Jeanne Griffith
Education and Public Welfare Division
February 18, 1987

FINANCING LONG-TERM CARE SERVICES FOR THE ELDERLY

I. INTRODUCTION

The phrase "long-term care" refers to a wide array of medical, social, personal, supportive, and specialized housing services needed by individuals who have lost some capacity for self-care due to chronic illness or physical or mental conditions which result in both functional impairment and physical dependence on others for an extended period of time. Major subgroups of individuals needing long-term care include the elderly and non-elderly disabled, the developmentally disabled (primarily the mentally retarded) and the mentally ill. This report focuses principally on long-term care services required by the elderly. Elderly persons, by virtue of their high risk of chronic illness that results in disability and functional impairment, are the primary recipients of long-term care in this country. 1/

The range of chronic illnesses and conditions resulting in the need for supportive long-term care services is extensive. Unlike acute illnesses, which occur suddenly and are usually resolved in a relatively short period of time, chronic conditions are of an extended duration and may be difficult to treat medically except to maintain the status quo of the patient. Although chronic conditions occur in individuals of all ages, their incidence, especially

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1/ Doty, Pamela, Korbin Liu and Joshua Wiener. An Overview of Long-Term Care. Health Care Financing Review, v. 6, no. 3, spring 1985. p. 69.

as they result in disability, increases with age. 2/ These conditions may include heart disease, strokes, arthritis, and vision and hearing impairments. Dementia, the chronic, often progressive loss of intellectual function, is also a major cause of disability in the elderly. 3/ At least half and perhaps as many as 70 percent of patients with dementia have Alzheimer's disease, a chronic progressive primary neurologic degeneration of unknown cause, which increases in prevalence with advancing age and for which there is currently no effective treatment. 4/

The presence of a chronic illness or condition alone does not necessarily result in a need for long-term care. For many individuals, their illness or condition does not result in a functional impairment or dependence and they are able to go about their daily routines without major hindrance or need for assistance. 5/ It is when the illness or condition results in a functional or activity limitation that long-term care services may be required. Limitations can vary in severity and prevalence. For example, a chronic condition may result in dependence in certain basic self-care functions such as bathing, dressing, eating, toileting, and/or mobility from one place to another. These are referred to as limitations in "activities of daily living" (ADLs). A second set of measures reflecting lower levels of disability in the performance of a daily routine are often referred to as limitations in

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2/ Rice, Dorothy and Carroll Estes. Health of the Elderly: Policy Issues and Challenges. Health Affairs, v. 3, no. 4, winter 1984. p. 29.

3/ Rowe, John. Health Care of the Elderly. New England Journal of Medicine, v. 312, no. 13, Mar. 28, 1985. p. 831.

4/ Rowe, p. 831.

5/ Long Term Care: Background and Future Directions. Health Care Financing Administration, Department of Health and Human Services, Jan. 1981, HCFA 81-20047. p. 4.

"instrumental activities of daily living" (IADLs). 6/ These include such functions as shopping, cooking, cleaning, managing money, and taking medicine. For example, certain individuals may not have limitations in basic self-care functions, but may not be able to clean or shop without some kind of assistance. Other individuals may suffer from a chronic condition or multiple conditions resulting in limitations in both ADLs and IADLs and therefore require a number of specific long-term care services.

Long-term care services include a wide variety of health and social services provided in an institution, in the community, or in the home. Services range from medical and therapeutic services for the treatment and management of chronic illnesses and conditions to assistance with basic living services associated with shelter and meals, such as housekeeping and shopping, to personal care assistance, such as bathing, grooming, and toileting. Such services are generally provided by nurses, social workers, therapists, and a wide variety of unskilled personnel, such as homemakers, nurses aides, and volunteers. Community-based services can be provided formally by agencies or organizations that are paid for their services, or informally by family or friends who offer assistance without compensation. By far, the great majority of long-term care is provided informally by family or friends.

The projected growth of the elderly population, combined with large and increasing Federal and other public expenditures for long-term care services, especially nursing home services, has generated over the years substantial legislative interest in altering the way in which long-term care services are financed. This report discusses the financing of long-term care services,

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6/ Liu, Korbin and Kenneth Manton. Disability and Long-Term Care. A paper presented at the Methodologies of Forecasting Life and Active Life Expectancy Workshop. Bethesda, Maryland, June 25-26, 1985.

and especially the extent to which various Federal programs cover and fund these services. It also describes various proposals that have been advanced as alternative private financing schemes for long-term care.

II. SELECTED CHARACTERISTICS OF THE ELDERLY AND MEASURING THEIR NEED FOR LONG-TERM CARE

The need for long-term care services in the future will depend on a number of factors, including demographic changes in the Nation's population, economic conditions which affect an individual's ability to pay for services, levels of disability, and medical advances in the prevention and treatment of chronic conditions. Estimating the dimension of the need for long-term care is a difficult but critical task for policymakers. It is critical since large and increasing amounts of public dollars finance long-term care services. It is difficult because the impact of certain of these factors cannot be predicted with certainty. For example, medical advances may result in the prevention of certain chronic conditions, or simply in incremental improvements in their management. Medical and scientific advances can also lead to reductions in general mortality which would result in increases in the size of the potential long-term care population. This section provides information about certain demographic and income characteristics of the elderly population.

A. Growth of the Elderly Population

The aging of the Nation's population has dramatic implications for projections of need for long-term care services. The elderly population has grown much more rapidly in this century than has the remainder of the population. As table 1 shows, from 1900 to 1950, the total population doubled in size while the population aged 65 and over increased by four times; from 1950 to 1980, when the total population increased by 50 percent, the aged population doubled in size, to 25.5 million. Between 1980 and the year 2020, the total population is projected to increase by slightly more than 30 percent, while the elderly population is projected to more than double again. By 2020, the projected elderly population will be 51.4 million, 17.3 percent of the total population.

TABLE 1. Size of the Elderly Population, 1900 to 2020
(in thousands)

Year	Total U.S. population	65+ No.	65+ %	85+ No.	85+ %	Aged support ratio*
1900	76,303	3,084	4.0	123	0.2	7.6
1950	150,697	12,270	8.1	577	0.4	13.7
1980	226,505	25,544	11.3	2,240	1.0	18.6
2000	267,955	34,921	13.0	4,926	1.8	21.6
2020	296,597	51,422	17.3	7,081	2.4	29.3

* Ratio of 65+ plus population to working age population, 19-64 years, multiplied by 100.

Source: U.S. Department of Commerce. Bureau of the Census. Decennial Censuses of Population 1900-1980 and Projections of the Population of the United States by Age, Sex, and Race: 1983 to 2080 (Advance Report). Current Population Reports, Series P-25. No. 952. May 1984. Projections are middle series.

As a result of the rapid increase in the elderly population, their proportion of the population increased from 4.0 percent in 1900 to 11.3 percent in 1980; this is expected to increase to 13.0 percent by 2000. At the same time, the number of elderly in comparison to the number of persons in the working age population (persons aged 19-64) has increased substantially. The aged support ratio (that is, the ratio of the 65+ population to the working age population 19-64 years) increased from 7.6 in 1900 to 18.6 in 1980 and is expected to increase to 29.3 by 2020.

Despite the overall growth in the 65 plus group, the most critical demographic factor with implications for the future of long-term care service utilization is the startling pace of increase in the oldest segment of society. The "old-old," persons 85 and over, are currently the fastest growing age group in the U.S. population. This group represented only 0.2 percent of the total population in 1900, but increased to 1.0 percent in 1980; by 2020, they are projected to be 2.4 percent of the population, and nearly 14 percent of the elderly population (up from about 9 percent in 1980).

B. Economic Characteristics of the Elderly

1. Income

In 1985, the median income of families headed by persons 65 or older was $19,162; the median income of an unrelated individual in the same age group was $7,568. (There were 10.1 million such families and 8.9 million such unrelated individuals.) 7/ This compares to $27,735 for all families and $11,808 for all unrelated individuals. Data from the 1980 Census of Population and Housing show that the cash income of the elderly is lower in each older age group. 8/

7/ U.S. Bureau of the Census. Current Population Reports. Series P-60, no. 154. Money Income and Poverty Status of Families and Persons in the United States: 1985 (Advance Data from the March 1986 Current Population Survey). U.S. Govt. Print. Off., Washington, D.C., 1986. p. 12.

8/ U.S. Bureau of the Census. 1980 Census of Population and Housing. Public Use Microdata Sample. Special tabulations.

Married couples with a head aged 65-69 had a median income of $18,400, compared to $11,200 for those 85 and over. Men aged 65 to 69 and living alone had a median income of $8,200, while those 85 and over had incomes of $6,000; the comparable figures for women living along were $6,800 and $5,200, respectively. In 1984, the after-tax, disposable income of elderly households, adjusted for family size, was less than that of households with heads aged 50 to 64, but higher than all other households. 9/ Among the younger old, and particularly among those who will become old in the next decade, pension coverage is higher than was the case for the old-old. At the same time, early retirement is an increasingly common phenomenon.

2. Poverty Rates

The poverty rates for the elderly have shown a dramatic decline over the last 25 years. In 1959, the poverty rate for the elderly was 35.2 percent and by 1984 the rate had fallen to 12.4 percent, the lowest rate ever recorded for that group. In addition, from 1982 to 1985, the poverty rates among the elderly population in general have been lower than those of the rest of the population. In 1985, 12.6 percent of those 65 and over were poor in comparison to 14.0 percent of the entire population. (In 1985, the estimated poverty threshold for persons 65 years and over living alone or in households with no other family members was $5,156, and for two person families whose head was 65 years and over, it was $6,503.) These aggregate figures, however, mask important differences within both the elderly and the remainder of the population. The poverty rate among other adults (persons 22 to 64), for example, was 10.7

9/ U.S. Bureau of the Census. Current Population Reports. Series P-23, no. 147. After-Tax Money Income Estimates of Households: 1984. U.S. Govt. Print. Off., Washington, D.C., 1986. p. 31.

percent in 1985; the rate for the entire population is inflated by the very high rates of poverty among children. 10/

There are specific groups among the elderly that are at substantially greater risk of poverty. Poverty rates increase sharply with age; in 1980, the rates varied from 13.6 percent among those 65 to 69 to 27.3 percent among those 85 and over. Women have rates that are two to three times as high as men; women 85 and over had poverty rates of 34.1 percent compared to 17.2 percent among men. Finally, elderly who live alone have much higher rates than do persons living with a spouse or with children. People aged 85 and over living alone in 1980 had a poverty rate of 36.8 percent, in contrast to a rate of 12.4 percent among those living with a spouse. 11/ In all cases, the poverty rates are much lower among the young-old (persons 65-74 years of age).

3. Net Worth

In 1984, the net worth of the elderly (including equity in their homes and automobiles as well as other financial assets and subtracting any debt) also varied by age group. Households with heads aged 65 to 69 on average had greater net worth ($66,600) than households with heads 70 to 74 ($60,600), or households 75 and over ($55,200). The age group that will become elderly in the next decade, those 55 to 64, had a higher level of net worth ($73,700) than their immediate seniors, and also a higher level than younger age groups

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10/ Money Income and Poverty Status of Families and Persons in the United States: 1985. pp. 27,33.

11/ The 1980 Census of Population and Housing. Special Tabulations.

($56,800 for those 45 to 54 and $35,600 for those 35 to 44). 12/ Beginning with those aged 55 to 64, an increasing share of net worth is in the form of home equity. This ranges from just over 50 percent of net worth among those aged 55 to 64 to 57 percent among those 75 and over.

4. Future Resources

A number of sources indicate that in the future, the new elderly will have increasingly higher incomes and assets. These predictions may have implications for the ability of the elderly to finance long-term care. Median income among the elderly as a whole has been projected to rise (controlling for inflation) from 10 to 20 percent from 1980 to 1995 (assuming 1.0 to 1.5 percent average annual growth in income among the general population). 13/ Under the same growth assumptions, income among persons 55 to 64 is projected to increase from between 15 and 20 percent in the same period. Asset levels are even more difficult to project, but because of the improved historical personal economic experiences of the future aged who have lived through the post-World War II prosperity, some anticipate that their levels of resources will be considerably greater than past generations of elderly. 14/

12/ U.S. Bureau of the Census. Current Population Reports. Series P-70, no. 7. Household Wealth and Asset Ownership: 1984 (Data from the Survey of Income and Program Participation). U.S. Govt. Print. Off., Washington, D.C., 1986. p. 19.

13/ U.S. Bureau of the Census. Current Population Reports. Series P-60, no. 122. Illustrative Projections of Money Income Size Distributions for Households: 1980 to 1995. U.S. Govt. Print. Off., Washington, D.C., 1980. Series C. 1.0 and 1.5 percent growth in household income.

14/ Etheredge, Lynn. An Aging Society and the Federal Deficit. Milbank Memorial Fund Quarterly/Health and Society, v. 62, no. 4, 1984. p. 527.

Although the relative well-being (measured with income and assets) of the future elderly may on average be greater than that of recent generations of elderly, there will also continue to be large differences among the various groups of the elderly. Some of the differences will be the same as those described above, based either on lifetime differences of individuals or on sudden or gradual changes in family status or available sources of income and assets. Even if poverty rates are substantially lower than they currently are, there may be more poor elderly than there are now, because of the increasing numbers of elderly people. For example, if poverty rates among the elderly drop 20 percent by the year 2000, to 10.0 percent (from the current 12.6 percent), there would still be 3.5 million poor elderly--compared to 3.5 million in 1985. If poverty rates were to remain constant, there would be 4.4 million poor elderly in 2000. These factors will continue to exert pressure on public sector long-term care programs.

C. Utilization of Institutional and Community-Based Long-Term Care Services

Based on the projected growth of the elderly population and current utilization patterns of institutional and community long-term care services, major increases in the demand for long-term care can be anticipated for the future. In 1985, approximately 1.4 million elderly persons were residents of nursing homes. This is about five percent of the total elderly population. With current utilization, the National Center for Health Statistics has estimated that the number of elderly nursing home residents will increase by 58 percent from 1978 to 2003 when constant mortality is assumed and by over 115 percent when declining mortality is assumed. 15/ Another study has estimated that between 1985 and 2000, the nursing home population will increase by 47 percent from 1.4 to 2.1 million, and by 2040, it will more than double to 4.4 million. 16/ Analysis of nursing home utilization has found a high degree of variance in the length-of-stay patterns among nursing home residents. The majority of persons entering a nursing home (75 percent) stay less than 1 year, and one-third to one-half of all entrants stay less than 3 months. About one-fourth of all persons entering a nursing home stay beyond 1 year, and relatively few (14-17 percent) stay more than 3 years. 17/

Rates of nursing home utilization are most dramatic when broken down by age group. The old-old (those 85 years and over) show much higher nursing home utilization rates than their younger counterparts. As table 2 shows, for women 85 years and over the rate of nursing home use per 1000 population is 251.5 as compared to only 15.9 for females 65-74, and 80.6 for females 75-84. A similar pattern exists for men, although their nursing home utilization rates are lower.

15/ Changing Mortality Patterns. Health Services Utilization and Health Care Expenditures: United States 1978-2003, Analytical and Epidemiological Studies Series 3, no. 23, National Center for Health Statistics, Department of Health and Human Services, Pub. No. (PHS) 83-1407, Sept. 1983. p. 20.

16/ Manton, Kenneth and Korbin Lin. The Future Growth of the Long-Term Care Population: Projections Based on the 1977 National Nursing Home Survey and the 1982 Long-Term Care Survey. Unpublished paper, 1984. p. 20.

17/ Cohen, Marc, Eileen Tell, and Stanley Wallack. The Lifetime Risks and Costs of Nursing Home Use among the Elderly. Medical Care, v. 24, no. 12, Dec. 1986. p. 1169.

TABLE 2. Age-Specific Rates of Nursing Home Utilization per 1,000 Population, by Sex

Sex and age	Rates per 1,000 population Nursing home residents
Male	
65-74	12.7
75-84	47.4
85+	140.0
Total 65+	30.7
Female	
65-74	15.9
75-84	80.6
85+	251.5
Total 65+	59.7

Source: Rice, Dorothy and Jacob J. Feldman. Living Longer in the United States: Demographic Changes and Health Needs of the Elderly. Milbank Memorial Fund Quarterly/Health Society, v. 61, no. 3, 1983. Table 6. p. 376. Data are from the National Nursing Home Survey of 1977.

For every person 65 years of age and over residing in a nursing home, there are twice as many persons living in the community requiring similar levels of care. 18/ The 1979 National Health Interview Survey found that 12 percent of the population age 65 and over needed the help of another person in carrying out everyday activities and managed to live in the community despite chronic disability. 19/ Analysis from the 1982 National Long-Term Care Survey found approximately 4.6 million non-institutionalized elderly Americans, or 18 percent of the over 65 population, had limitations in ADLs

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18/ Doty, Pamela, Korbin Liu, and Joshua Wiener. And Overview of Long-Term Care. Health Care Financing Review, v. 6, no. 3, spring 1985. p. 70.

19/ Feller, Barbara. Americans Needing Help to Function at Home. National Center for Health Statistics Advance Data, no. 92, Sept. 14, 1983. p. 7.

and IADLs. 20/ As discussed above, limitations in ADLs reflect dependence in certain basic self-care functions such as bathing, dressing, eating, etc., and limitations in IADLs refer to lower levels of disability in the performance of a daily routine, including shopping, cooking, and cleaning. The 1982 Long-Term Care Survey found that two-thirds of the 4.6 million disabled noninstitutionalized elderly living in the community were moderately impaired with one or two ADL limitations or only IADL limitations. About 850,000 elderly individuals were residing in the community with severe limitations (five or six ADLs).

This same analysis found that most of these disabled elderly received personal assistance in activities of daily living from spouses, children or other informal sources of support. 21/ Of the 4.6 million disabled elderly in the community, more than 70 percent (3.2 million) relied exclusively on nonpaid sources. This finding corresponds to other research that has estimated that between 60 and 80 percent of the care received by the impaired elderly is provided by relatives and friends who are not compensated. 22/

There is evidence that informal care giving is one of the key factors in delaying or preventing institutionalization of the frail elderly. However, the aging of the Nation's population has important implications for the availability of informal family sources of support for long-term care. Estimates from the 1982 National Long-Term Care Survey show that the average age of caregivers of

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20/ Liu, Korbin, Kenneth Manton, and Barbara Liu. Home Care Expenses for the Disabled Elderly. Health Care Financing Review, v. 7, no. 2, winter 1985. p. 52.

21/ Ibid.

22/ Long-Term Care: Background and Future Directions. Health Care Financing Administration, Department of Health and Human Services. Jan. 1981, HCFA 81-20047.

the impaired elderly was 57 years. More striking is the finding that one-quarter of caregivers was aged 65-74, and 10 percent was 75 years or older. These data support the view that informal services are largely provided by the "young old" to the "old old." 23/ As the population ages, very old chronically ill parents with children who themselves are retired or chronically impaired will become more common. 24/ Researchers have noted that the probability of young elderly (aged 65-69) women having at least one surviving parent aged 85 or older will more than double over the next 60 years. 25/ This factor has tended to underline the need for a range of formal services which can support caregivers.

23/ U.S. Congress. House. Select Committee on Aging. Exploring the Myths: Caregiving in America. Pub. no. 99-611, Jan. 1987, Washington, D.C.

24/ Long-Term Care: Background and Future Directions. p. 12.

25/ Soldo, Beth J. and Kenneth G. Manton. Health Status and Service Needs of the Oldest Old: Current Patterns and Future Trends. Milbank Memorial Fund Quarterly/Health and Society, v. 63, no. 2, spring 1985. p. 310.

III. PUBLIC SECTOR PROGRAMS FOR FINANCING AND DELIVERY OF LONG-TERM CARE SERVICES

Implicit in any discussion of long-term care policy is the fact that large amounts of public dollars currently finance long-term care services, and that even greater amounts will be spent in the future as the elderly population, especially the very old, increases. Aggregated data on spending for all nursing home and non-institutional long-term care services under the complete array of Federal, State and local programs are not easily available. At least 80 Federal programs assist persons with long-term care problems, either directly or indirectly through cash assistance, in-kind transfers, or the provision of goods and services. In addition, differences in definitions of services to be included in long-term care and inconsistent reporting across programs make aggregation of expenditure data very difficult.

However, it is generally agreed that most of the public sector's expenditures for long-term care services are for nursing home or other institutional care. In 1985, the Nation spent $35 billion for nursing home care, accounting for 9.5 percent of total personal health care expenditures. Approximately 47 percent of the Nation's expenditures for nursing home care, or $16.5 billon, was financed by Federal, State, and local governments.

By far the largest portion of public expenditures for nursing home care is financed by the Medicaid program for the poor and medically indigent. In 1985, Federal, State, and local Medicaid expenditures for nursing home care amounted to $14.7 billion. This represented 42 percent of total national spending on nursing home care and 89 percent of public spending for nursing home care in 1985. Medicaid's expenditures for nursing home care also represented a significant portion of total Medicaid spending. In 1985, Medicaid nursing home expenditures amounted to about 37 percent of total Medicaid spending for all health services covered under the program. In addition, an analysis of Medicaid expenditures found that 27 States spent 50 percent or more of their Medicaid budgets on nursing home care in 1982. 26/

It should be noted that the share of nursing home care financed by public programs has been declining since 1979, from 56 percent to 47 percent in 1985. In part, this can be explained by vigorous State efforts to control expenditures for nursing home care under their Medicaid programs. 27/ These efforts have included limitations on the construction of nursing home beds, either through requirements to certify the need for more beds before construction can begin, or through the prohibition of construction or addition of beds altogether (often referred to as moratoriums). States have also used various forms of utilization review and pre-admission screening mechanisms to limit inappropriate use, as well as reimbursement policies to control costs per day of care provided.

By way of contrast, the Medicare program for the aged and disabled accounts for only a small portion of the Nation's expenditures for nursing home care. Medicare's expenditures amounted to $600 million and represented less than 2 percent of national spending and 3.6 percent of public spending for nursing home care in 1985.

26/ Short-Term Evaluation of Medicaid: Selected Issues. Department of Health and Human Services, Health Care Financing Administration, Office of Research and Demonstrations, no. 84-9. July 1, 1984.

27/ Nursing Home Reimbursement under Medicaid. Intergovernmental Health Policy Project. Washington, D.C. Feb. 1986. p. 2.

Expenditures for non-institutional community-based services are relatively small compared to spending for nursing home services. Whereas nursing home care accounted for about 37 percent of total Medicaid expenditures for health care services in 1985, home health care accounted for only 3.0 percent of total Medicaid spending in that year and amounted to approximately $1.1 billion. One State (New York) alone accounted for slightly more than 60 percent of total Medicaid home health expenditures.

Medicare's spending for home health care benefits is also a small proportion of total program expenditures. In 1985, home health expenditures amounted to 3.2 percent of total program expenditures.

It should be noted that while its share remains small, home health care has become one of the fastest growing components of both the Medicare and Medicaid budgets. Between 1974 and 1985, home health care expenditures under Medicare increased from $138 million to $2.27 billion. This represented a 29 percent average annual compound rate of growth. Medicaid expenditures for home health also increased rapidly--from $31 million in 1974 to $1.1 billion in 1985, a 38 percent average annual compound rate of growth.

While the Medicaid program is the predominant Federal program supporting long-term care services, a variety of social service programs provide community-based services which may prevent or delay institutionalization. Chief among these are the Social Services Block Grant program and the Older Americans Act. While their total resources are small in comparison with total Medicaid expenditures devoted to both institutional and community-based long-term care services, in many communities these two programs represent an important source of services to the frail elderly or fill gaps in services not met by either the Medicare or Medicaid programs.

All States provide a number of home and community-based long-term care services for diverse client groups, including children, disabled, and the elderly, through the Social Services Block Grant (SSBG) program under title XX of the Social Security Act. Such services may include homemaker, home health aide, chore, adult day care services, and adult foster care. Due to the lack of Federal reporting requirements, virtually no national data are available on recipients of services and expenditures under the program. However, home-care type services for needy groups is the one service provided by all States.

Home care, including homemaker, chore, and personal care services, is one of the major service categories under title III of the Older Americans Act. For FY 1985, it was estimated that the program would provide homemaker services to almost 672,000 older persons and home health aide services to 159,000 other persons. The Older Americans Act also authorizes a home-delivered meals program for homebound elderly. An estimated 76 million home-delivered meals were served under auspices of the program during FY 1985.

A. Major Federal Programs and Activities Supporting Long-Term Care Services

As noted above, at least 80 Federal programs assist persons with long-term care problems, either directly or indirectly through cash assistance, in-kind transfers, or provision of goods and services. These programs often respond in a manner that is problem-specific, categorical in nature, or targeted at specific client groups. For example, certain programs provide health services while excluding social services; others are oriented to the elderly to the exclusion of the younger disabled. Some programs carry income eligibility requirements, others do not.

This section describes selected Federal programs--Medicaid, Medicare, the Social Services Block Grant (SSBG), Older Americans Act, and Supplemental Security Income (SSI) programs--which address the health and social services needs of the elderly. Taken together, these programs constitute the major focus of Federal financial support presently available for both community-based and institutional long-term care services. The differing characteristics of these programs reflect what some observers point out to be the uncoordinated nature of Federal support for long-term care services.

Not discussed here are a host of other Federal programs dealing with such components of the long-term care spectrum as housing, transportation, tax policy as well as services provided through the Veterans Administration (VA). It should be noted, however, that numerous long-term care benefits are offered to veterans through the VA, including nursing home care, domiciliary care, outpatient clinics, and adult day health services, as well as cash payments for aid and attendance for certain severely disabled veterans. Services are offered directly by the VA and are also provided on a contract basis in non-VA hospitals and community nursing homes, and on a grant basis in State veterans' home facilities. Issues surrounding the financing and delivery of long-term care services to the veteran population are of increasing concern to the VA because of the growing number of older veterans. By the year 2000, approximately two out of every three males age 65 or older will be veterans and the VA is predicting dramatic increases in the need for and utilization of various long-term care services by the veteran population.

The discussion immediately below summarizes some of the major differences of the Medicaid, Medicare, Social Services Block Grant (SSBG), Older Americans Act, and SSI programs in their approach to health and social services in general and long-term care in specific. This discussion is followed by a more detailed description of each of these programs.

° PROGRAM GOALS. Medicaid is the major Federal program financing health care services for certain low income persons. While it provides health care benefits, and to a limited degree, medically related social services, to certain eligible persons with chronic care needs, it is not designed to support the full array of long-term care services on a systematic basis. Its prinicpal form of support for long-term care services is for nursing home care. Medicare, on the other hand, is a nationwide health insurance program for the aged and disabled and is intended primarily to address acute medical care needs. To the extent that it provides coverage for certain long-term care services, it does so with the intent of reducing the need for more intensive and expensive acute care services; the program was not designed to respond specifically to chronic care needs of the elderly over a sustained period of time. The SSBG program is designed to assist families and individuals in maintaining self-sufficiency and independence; however, the program is generally limited to the provision of community-based social services selected and defined by each State and does not support institutional care. The Older Americans Act is intended to foster the development of a broadly defined, comprehensive and coordinated service system for the aged; however, it is limited in its ability to have a significant impact on long-term care due to its small level of resources as compared to other programs. The SSI program's purpose is to provide an income floor for needy aged, blind, and disabled individuals; it provides cash payments but not services.

- ADMINISTRATIVE AUTHORITY AND FINANCING MECHANISMS. The Medicare program is administered and financed at the Federal level with uniform national standards. The Medicaid, SSBG, and Older Americans Act programs are shared Federal-State programs with States responsible for implementation of Federal legislation and regulations. The SSI program is administered at the Federal level but allows States to augment the Federal SSI payment and this portion of the program may be federally or State-administered. The Medicaid and Older Americans Act programs carry specific requirements for States to match Federal funds, whereas the SSBG does not. By virtue of their statutory obligations to beneficiaries, Medicare, Medicaid, and SSI represent uncontrollable expenditures in the Federal budget. In contrast, the total funding available for programs under the Older Americans Act is subject to an annual limit imposed through the appropriations process. Although the SSBG is considered an entitlement program to States, it carries a statutorily imposed Federal expenditure ceiling.

- SERVICE BENEFITS, DEFINITIONS, AND STANDARDS. As a general rule, Medicare and Medicaid provide reimbursement primarily for medical and health care services; however, in certain instances Medicaid reimbursement is available for social service components of health care services, e.g., under State options for personal care or adult day care services and under home and community-based waiver provisions. The SSBG program provides reimbursement for social services only but will provide coverage for medical care when such care is "integral but subordinate" to the provision of a social service. Funding under title III of the Older Americans Act is to be used for the development of a service delivery system for older persons, focusing on supportive and nutritional services. Recipients of SSI receive a cash payment which is federally determined but States may decide how much and for what purpose to supplement the Federal payment. Definitions for similar or complementary services vary among programs and sometimes among programs within a single State. Certain service definitions are established at the State level, or at the local level by individual service providers. Similarly, standards for services may be established upon legislative specifications.

- ELIGIBILITY. Entitlement for Medicare is generally based on Social Security status. Eligibility for Medicaid is linked to actual or potential receipt of cash assistance under the federally-assisted Aid to Families with Dependent Children program and the SSI program for the aged, blind, and disabled. The SSBG does not require that applicants or recipients meet income eligibility guidelines, although States may set standards. The Older Americans Act program prohibits income testing for services; however, funds under the program must be directed toward those with the greatest social or economic need. Eligibility for the Federal payment portion of SSI is based on federally established income and asset rules.

1. Medicaid--Title XIX of the Social Security Act

The Medicaid program is a Federal-State matching program providing medical assistance for certain low-income persons. Each State administers its own program and, subject to Federal guidelines, determines eligibility and scope of benefits. In general, each State also determines the payment rate for services provided to Medicaid recipients. The Federal Government's share of medical expenses is tied to a formula based upon the per capita income of the State. As a minimum, the Federal Government will pay 50 percent of the costs of medical care; this amount ranges up to 78 percent in the lower per capita income States.

The States vary greatly with regard to services they include in their plans and groups eligible to receive these services. For example, major long-term care services provided under Medicaid include intermediate care facility (ICF) services, skilled nursing facility (SNF) services, and home health services. Other Medicaid services sometimes associated with the needs of long-term care patients include: private-nursing services, clinic services, physical therapy and related services, inpatient care for patients 65 years of age or older in institutions for mental diseases or tuberculosis, inpatient psychiatric services for individuals under the age of 21, personal care services at home, and adult day health services. However, not all States cover these services equally. In addition, States may cover certain other home- and community-based services under special waiver programs reviewed and approved by the Secretary of Health and Human Services.

Medicaid law requires that States cover under their programs the "categorically needy"--all persons receiving assistance under the Aid to Families with Dependent Children (AFDC) program and most persons receiving assistance under the SSI program. States may also cover additional persons as categorically needy. These might include persons who would be eligible for cash assistance, except that they are residents in medical institutions, such as skilled nursing or intermediate care facilities.

In addition to the categorically needy, States may at their option cover the "medically needy," persons whose income and resources are large enough to cover daily living expenses, according to income levels set by the State, but not large enough to pay for medical care. If the income and resources of the "medically needy" individual are above a State-prescribed level, the individual must first incur a certain amount of medical expense which lowers the income to the medically needy levels (so-called "spenddown" requirement). Thirty-two States and jurisdictions have medically needy programs that can cover the elderly. As a result of State variations such as these, persons with identical circumstances may be eligible to receive Medicaid benefits in one State but not in another; even individuals in the same State with similar incomes may not be equally eligible for benefits due to welfare rules.

Observers have noted that Medicaid's eligibility policies and benefit structure have actually created financial incentives to use nursing homes rather than community services. In general, Medicaid support to the chronically impaired elderly living in the community has usually been quite limited. In addition, certain elderly poor who are ineligible for Medicaid while living in the community may become eligible once they enter a nursing home because the State has a higher income eligibility standard for nursing home residents. Others become eligible for Medicaid once they deplete their resources after entering the nursing home as privately paying patients. A 1983 GAO report reviewed studies showing that one-quarter to two-thirds of Medicaid patients in nursing homes initially entered as private paying patients and subsequently converted to Medicaid. 28/ Another analysis completed for the House Select Committee on Aging found that in Massachusetts 63 percent of elderly persons aged 66 and older living alone in the community will deplete their assets after only 13 weeks in a nursing home, and for married couples aged 66 years and older, 37 percent will do so within 13 weeks if one spouse requires nursing home care. 29/

In order to allow States to broaden coverage for a range of community-based services and to receive Federal reimbursement for these services, Congress in 1981 passed legislation authorizing the Secretary of the Department of Health and Human Services (DHHS) to approve special State applications to provide such services under their Medicaid programs. Specifically, the

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28/ Medicaid and Nursing Home Care: Cost Increases and the Need for Services are Creating Problems for the States and the Elderly. U.S. General Accounting Office, GAO/IPE-84-1. Oct. 21, 1983. p. 25-26.

29/ U.S. Congress. House. Select Committee on Aging. America's Elderly at Risk. Pub. No. 99-508, July 1985, Washington, D.C. Research analysis completed for the Committee by Dr. Laurence Branch, Dr. David Friedman, and Ms. Elinor Socholitzky.

Secretary is authorized to waive certain Medicaid requirements to allow States to provide a broad range of home and community-based long-term care services to individuals who would otherwise require, and have paid for by Medicaid, the level of care provided in a hospital, skilled nursing facility, or intermediate care facility. Waivers to provide home and community-based services are frequently referred to as 2176 waivers after the section in the Omnibus Budget Reconciliation Act of 1981 which originally authorized them. Under the 2176 waiver program, the Secretary of HHS (and, on behalf of the Secretary, the Health Care Financing Administration (HCFA), which administers the Medicaid program) is allowed to waive two specific Medicaid requirements: (1) a requirement that Medicaid services be available throughout a State and (2) a requirement that covered services be equal in amount, duration, and scope for certain Medicaid recipients. By allowing the Secretary to waive these requirements, the enabling legislation intended to provide the States flexibility to offer selected 2176 home and community-based services in only a portion of the State, rather than in all geographic jurisdictions as would be required absent the waiver, and to offer selected services to certain State-defined individuals eligible for Medicaid assistance, including the aged, blind, disabled, mentally retarded, and mentally ill, rather than offering such services to all persons in particular groups. In addition, States have been able to extend to waiver participants the more liberal Medicaid income eligibility rules that may be applied to persons in institutions.

The expanded services which States may offer under an approved waiver include medical and medical-related services as well as social services. Prior to the implementation of the 2176 waiver program, Medicaid services available to chronically ill or disabled individuals living in the community were generally restricted to medical and medical-related services. The waiver authority acknowledges that a wide variety of other non-medical services may be needed in order to prevent or avoid institutionalization. For this reason, services traditionally considered to be social services are covered in the waiver authority. These include case management (commonly understood to be a system under which responsibility for locating, coordinating, and monitoring a group of services rests with a designated person or organization), homemaker and chore services, adult day health, and respite care.

The additional flexibility Congress authorized under the waiver as to services, eligibility, and geographic areas to be covered was qualified by a concern about the costs of home and community-based care to be provided under the amendment. Therefore, the law included a requirement that States demonstrate that the costs of services for individuals receiving home and community-based services not exceed the cost to Medicaid of care in institutions. HCFA regulations implementing the waiver program require States to demonstrate cost-effectiveness through a waiver formula in which States show that Medicaid expenditures for all services provided to individuals under the waiver will not, in any year of the waiver period, exceed Medicaid expenditures that would be incurred for these individuals in the absence of the waiver. This demonstration of cost-effectiveness is, as a result, extremely dependent upon assumptions regarding growth rates in nursing home utilization and expenditures which would otherwise occur if the waiver is not approved. 30/ Since the initial implementation of the program, HCFA has become increasingly stringent in its require-

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30/ Burwell, Brian. Home and Community-Based Care Options under Medicaid. Affording Access to Quality Care: Strategies for State Medicaid Cost Management. National Governors' Association Center for Policy Research. July 1986. p. 74.

ments for detailed and specific documentation that utilization of nursing homes by Medicaid recipients would actually increase but for the waiver. This documentation may require, for example, submission of certificate-of-need applications, approved or pending, showing that nursing home beds would be built to meet estimates of projected utilization. [31]

As of January 31, 1987, 44 States had 105 approved waiver programs in operation. (For more information about the 2176 waiver program, see CRS white paper, Medicaid 2176 Waivers for Home and Community-Based Care, 85-817 EPW.)

2. Medicare--Title XVIII of the Social Security Act

Medicare is a Federal health insurance program with a uniform eligibility and benefit structure throughout the United States. The program covers most individuals entitled to Social Security benefits, persons under 65 entitled to Federal disability benefits, and certain individuals with end-stage renal disease. Coverage is available to persons without regard to their income or assets.

Medicare is generally not regarded as a program intended to provide support for long-term care. Its coverage is focused primarily on acute care, particularly hospital and surgical care and accompanying periods of recovery. For example, Medicare's hospital benefit covers only 90 days of care per spell of illness and an additional lifetime reserve of 60 days. To the extent that Medicare covers certain kinds of long-term care services, it does so only where a need for skilled care is demonstrated. Program coverage of nursing home care is limited to 100 days of skilled nursing facility (SNF) services following a hospital stay of at least three consecutive days. The benefit is further limited in that the patient must be in need of skilled nursing care on a daily basis for treatment related to a condition for which he or she was hospitalized. The SNF benefit is subject to a daily patient copayment after the 20th day of care. The program pays for neither intermediate care facility services nor custodial care in a nursing home. For those persons receiving SNF benefits, Medicare covered an average of 27 days of care in 1984. 32/ In addition, the program paid for less than 2 percent of the Nation's nursing home expenditures in 1985.

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[31] Ibid.

Similarly, Medicare pays for limited amounts of community-based long-term care services, primarily through the program's home health benefit. To qualify for home health services, the Medicare beneficiary must be confined to his or her home and under the care of a physician. In addition, the person must be in need of part-time or intermittent skilled nursing care, or physical or speech therapy. Services must be provided by a home health agency certified to participate under Medicare, according to a plan of treatment prescribed and reviewed by a physician. There is no statutory limit on the number of home health visits covered under Medicare. Nor is the patient subject to any cost-sharing, e.g., deductibles or coinsurance, for covered home health services.

Once the beneficiary qualifies for Medicare's home health benefit, the program will pay for the following services:

--part-time or intermittent nursing care provided by, or under the supervision of, a registered professional nurse;

--physical, occupational, or speech therapy;

--medical social services provided under the direction of a physician;

32/ Medicare: Use of Skilled Nursing Facilities, 1984. Health Care Financing Administration. Office of Research and Demonstrations. Research Brief no. 86-4. p. 2.

--medical supplies and equipment (other than drugs and medicines);

--medical services provided by an intern or resident enrolled in a teaching program in a hospital affiliated or under contract with a home health agency; and

--part-time or intermittent services provided by a home health aide, as permitted by regulations.

Persons receiving home health services under the Medicare program used an average of 27 visits in 1984. 33/

In addition to these SNF and home health care benefits, Medicare covers a range of long-term care services, and especially home care services, for terminally ill beneficiaries. These services, authorized in 1982 and referred to as Medicare's hospice benefit, are available to beneficiaries with a life expectancy of 6 months or less. Hospice care benefits include nursing care, medical social services, physicians' services, counseling, therapy services, home health aide and homemaker services, medical supplies, including drugs and biologicals, and short-term inpatient care. HCFA estimates that Medicare expenditures for hospice care will amount to $15 million for FY 1985, and $35 million for FY 1986.

The introduction in FY 1984 of a prospective payment reimbursement system for inpatient hospital care under Medicare has raised a number of questions about its impact on the quality of care received by the elderly, including care available in long-term care settings covered by the program--SNFs, home health, and hospice. 34/ Moreover, concern has been raised about the effects

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33/ Kirby, Will, Vikki Latta, and Charles Helbing. Medicare Use and Cost of Home Health Services, 1983-84. Health Care Financing Review, v. 8, no. 1, fall 1986. p. 93.

34/ Post-Hospital Care: Efforts to Evaluate Medicare Prospective Payments Effects Are Insufficient. U.S. General Accounting Office, GAO/PEMD-86-10. June 1986. p. 10.

PPS has on the ability of community-based social service agencies, partially supported by the Older Americans Act and the Social Services Block Grant, to adjust their programs to meet the growing needs of hospital discharged patients for certain social services, such as home-delivered meals and a variety of other in-home services not covered by Medicare or Medicaid.

Medicare's prospective payment system (PPS) sets predetermined fixed payment rates for each hospital inpatient admission, based on the diagnosis-related group (DRG) into which that admission falls. This fixed payment provides hospitals with incentives to limit costs incurred for each Medicare patient admission, generally either by reducing lengths of stay and/or intensity or care provided.

Since the introduction of PPS, average lengths of stay in hospitals have decreased markedly for Medicare beneficiaries. To the extent that this decrease in length of stay represents a reduction in unnecessary acute care, one objective of PPS reform is being met. However, concern has been expressed about the availability and quality of care for those beneficiaries who may be discharged sooner from hospitals and who may need additional services that may or may not be covered by Medicare as SNF or home health care. GAO has identified a number of issues which must be evaluated in any assessment of the impact of PPS on post-hospital care: Have patients' post-hospital care needs changed since implementation of PPS? How are patients' needs being met? Are patients having access problems? How have long-term costs been affected? 35/ Currently little information exists to provide conclusive answers to these questions, although HCFA has sponsored a number of studies that are intended to address these issues.

In addition, limited studies have noted that earlier hospital discharges

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35/ Post-Hospital Care: Efforts to Evaluates Medicare Prospective Payment Effects Are Insufficient, p. 12.

are having a marked effect in some areas of the country on the demand for community-based social services. An early study, which attempted to measure the changes in the service delivery patterns and priorities of community-based long-term care services provided through the Older Americans Act since implementation of PPS, found increases in the length of service and varieties of in-home services required by the elderly. 36/ Other observers have pointed to growing pressures to use limited social services funding to respond to the needs of patients discharged sooner from hospitals under PPS, resulting in a reduction of services for other chronically ill or functionally impaired elderly living in the community who have not been discharged from a hospital and who require services to remain independent.

3. Social Services Block Grant Program--Title XX of the Social Security Act

Title XX of the Social Security Act authorizes a block grant to States for a wide range of social services to diverse population groups, including the aged, disabled, and children. States are allowed considerable discretion in their support of social services as long as the services are structured to meet the following goals of the program: achieving or maintaining economic self-support and self-sufficiency; preventing or remedying neglect, abuse, or exploitation; preventing or reducing inappropriate institutional care by providing for community-based care; and securing referral or admission for institutional care when other forms of care are not appropriate, or providing certain services, such as counseling or discharge planning, to individuals in

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36/ U.S. Congress. House. Committee on Education and Labor. DRGs and the Community-Based Long Term Care System. Testimony presented by the Southwest Long-Term Care Gernitology Center, University of Texas Health Science Center, Dallas. July 30, 1985.

institutions (excluding room and board). The SSBG provides reimbursement for social services only, but will provide coverage for medical care when such care is "integral but subordinate" to the provision of a social service.

States receive allotments of SSBG funds on the basis of the State's population, within a Federal expenditure ceiling. There are no requirements for use of title XX funds—States are provided relative freedom to spend Federal social service block grant funds on State-identified service needs. Legislation in the 98th Congress permanently increased the expenditure ceiling to $2.7 billion, effective in FY 1984; for FY 1985 through FY 1987, the appropriation level has been $2.7 billion.

The title XX program was significantly changed by provisions of P.L. 97-35, the Omnibus Budget Reconciliation Act of 1981, effective in FY 1982. Through FY 1981, the program contained certain limited requirements regarding the population to be served and the kinds of services to be provided to families and individuals. Under provisions of P.L. 97-35, States have been given much more discretion in determining the service population and services to be offered. The law eliminated requirements that States expend a portion of funds for welfare recipients, that services be limited to families with incomes below 115 percent of the State median income, and that fees be charged to persons with specified income levels. While previous State planning requirements were lessened, the law continues to require States to develop and make public a report on how funds are to be used prior to the State plan period, including information on the types of activities to be funded and the characteristics of individuals to be served.

The 1981 law also eliminated State reporting requirements; therefore, only very limited data are available as to the extent to which title XX supports long-term care services. According to a DHHS analysis of the States' FY 1986 pre-expenditure reports under title XX (a report on States' intended use of funds), home care services, which may include homemaker, chore, and home management services, were to be provided by virtually all States (to adults and children); adult day care by 31 States; and adult foster care by 18 States.

According to data compiled by the American Public Welfare Association for a limited number of States, in 1983 home-based services were provided to 11 percent of total title XX recipients, or about 307,000 persons of all ages. Home-based services accounted for about 14 percent of total expenditures, or $555 million (out of a total estimated amount of Federal and State funds of $4 billion). Adult day care services were provided to only 1 percent of total title XX recipients, or about 32,000 persons. They accounted for less than 1 percent of total expenditures. 37/ It should be noted that these data are for total title XX recipients; national data specific to the elderly and disabled population and by service are unavailable.

Although the SSBG represents the major social service program supported by the Federal Government, its ability to support significantly the long-term care population is relatively limited. Because it provides a variety of social services to a diverse population, the program has competing demands. Community care programs such as those supported by title XX are minimal when compared to Federal programs which support institutional care. For example, Federal funds available for all title XX activities in 1985 ($2.7 billion) were less than 30

37/ American Public Welfare Association (APWA). A Statistical Summary of the Voluntary Cooperative Information System (VCIS) Social Services Block Grant (SSBG): Data for 1983. October 1985. Data were compiled by the APWA under its VCIS under which States voluntarily report data on their social service programs. Data for recipients are for 32 States and expenditures are for 31 States. Total expenditures including a combination of State and local funds, Federal title XX funds, and other funds for 31 States, were an estimated $4 billion in 1983.

percent of total Federal nursing home expenditures in that year ($9.4 billion).

4. The Older Americans Act

The Older Americans Act carries a broad mandate to improve the lives of older persons in the areas of income, emotional and physical well-being, housing, employment, social services, civic, cultural, and recreational opportunities.

The purpose of title III of the Act, which authorizes formula grants to States for services to older persons, is to foster the development of a comprehensive and coordinated service system for older persons in order to (a) secure and maintain maximum independence and dignity in a home environment for older persons capable of self-care; (b) remove individual and social barriers to economic and personal independence for older persons; and (c) provide a continuum of care for the vulnerable elderly. Under title III, grants are made to State agencies on aging, which in turn award funds to 664 area agencies on aging, to plan, coordinate, and advocate for, a comprehensive service system for older persons. Title III supports a wide range of supportive services, as well as congregate and home-delivered nutrition services. Certain supportive services have been given priority by Congress, including in-home services, such as homemaker and home health aide, visiting and telephone reassurance, and chore. Each area agency is required to spend a portion of its supportive services allotment on these services. Other community-based long-term care services which may be provided under title III include case management, assessment, adult day care, and respite care, among others. Services under the title III program are to be provided to older persons without regard to income, although concentrated on those with the greatest social or economic need. Older persons are to be given the opportunity to contribute to the cost of services, but failure to do so cannot be a basis for denial of service.

Unlike the title XX program in which States receive a block of funds for unspecified social services, Congress makes separate appropriations of title III funds for supportive services, for congregate nutrition services (in which older persons receive meals and other services in a group setting), and for home-delivered nutrition services. States receive allotments of these funds according to the number of older persons in the State as compared to all States. The law gives States and area agencies flexibility to define the supportive services to be provided and to transfer funds among the three service categories. Total FY 1987 appropriations for title III are $829 million, with 67 percent of this amount appropriated for nutrition services. Only one-third of title III funds is specifically appropriated for the entire range of social services authorized by the Act, including community-based long-term care.

In-home services clearly represent an expenditure priority for the title III program. According to a National Data Base on Aging survey of 121 area agencies, in 1984, about one-quarter of funds controlled by area agencies (including Older Americans Act funds as well as non-Older Americans Act funds) was directed at in-home services. While a substantial portion of these funds was spent on the homedelivered meals component, which receives a separate appropriation under the Act, almost an equal proportion of the total spent on in-home services was devoted to housekeeping, personal care, and chore services. 38/

38/ Data are from a random sample survey of 121 area agencies on aging in 1984. Supplied by the National Data Base on Aging, a service of the National Association of State Units on Aging and the National Association of Area Agencies on Aging.

The ability of the Older Americans Act to have a significant impact on the long-term care system is limited due to its relatively small level of resources as compared to other programs. However, many State and area agencies have made strides to improve long-term care services through coordination activities with health and other social service agencies, and through the development of a social service infrastructure for the elderly at the local level. Some State agencies on aging have also acted as catalysts to reorganize community-based health and social services systems at the State and local levels so as to serve more effectively the long-term care population. For example, State agencies have developed case management and assessment systems through area agencies on aging and have supported services otherwise unavailable to the frail population. In other cases, State agencies on aging have been given responsibility for the administration of the section 2176 home and community-based waiver program under Medicaid. Although the amount of funding which title III devotes to home care services may represent a small fraction of the amount spent for home health services under Medicare and Medicaid, the title III program has the flexibility to fill gaps in services for persons otherwise unserved. Since Older Americans Act services may be provided without the restrictions required under Medicare and without certain income tests specified by Medicaid, in some cases title III may be used to serve persons whose Medicare and Medicaid benefits have been exhausted or who are ineligible for Medicaid.

Although the home-delivered nutrition program receives less Federal funding than the congregate nutrition program, in recent years States have increasingly shifted funds from the congregate program to the home-delivered and to the supportive services components. In FY 1986 States shifted over $47 million from the congregate nutrition appropriated amount of $322 million to the other service components. Reasons cited for this trend include the increasing age of the older population and increased demand for home-based services by a more frail and older population. A recent evaluation of the Older Americans Act nutrition program performed for the Administration on Aging has shown that recipients of home-delivered nutrition services tend to be older, poorer, and in worse health than congregate nutrition participants.

Another long-term care activity required under title III is the operation of a statewide long-term care ombudsman program. This authority requires State agencies to conduct the following activities: investigate and resolve complaints relating to the health, safety, welfare, and rights of institutionalized persons; monitor Federal, State and local laws, regulations, and policies with respect to long-term care facilities; provide information to public agencies regarding problems of older persons in long-term care facilities; and establish procedures for access to facilities' and patients' records, including protection of the confidentiality of such records. Ombudsman activities are to take place not only with respect to policies and practices of nursing homes but also activities in boarding homes. State agencies responsible for the ombudsman program have created sub-State programs to carry out these activities; in 1984 there were about 679 sub-State ombudsman programs. In FY 1984, about $14.3 million was expended for ombudsman activities under the Older Americans Act ($9.4 million in Federal funds and $4.9 million from State, local, and other funds). 39/

5. Supplemental Security Income Program--Title XVI of the Social Security Act

The Supplemental Security Income (SSI) program is a federally administered income assistance program authorized by title XVI of the Social Security Act.

39/ Administration on Aging. National Summary of State Long-Term Care Ombudsman Reports for FY 1984. February 11, 1986.

Enacted by the 1972 Social Security Amendments and implemented in 1974, it replaced previous programs of State income assistance for the aged, blind and disabled. The SSI program provides a minimum income level for aged, blind, and disabled persons whose countable income does not exceed the Federal maximum monthly SSI benefit. In 1987 the monthly Federal SSI benefit is $340 for an individual and $510 for a couple with no other income. SSI payments are made to individuals under uniform, nationwide rules with respect to income and assets, and definitions of blindness and disability. In 1987 an estimated 4.3 million individuals will receive Federal SSI payments (1.5 million aged persons and 2.8 million blind or disabled persons). 40/

The SSI program also allows States to supplement the Federal SSI payment through optional supplemental payments to individuals. All but eight States and jurisdictions provide some form of optional State payments. (These are Arkansas, Georgia, Kansas, Mississippi, the Northern Mariana Islands, Tennessee, Texas, and West Virginia.) Each State determines whether it will make a supplelemental payment, to whom, and in what amount. These State supplemental payments, also paid on a regular monthly basis, are intended to supplement the basic Federal SSI payment for food, shelter, clothing, utilities, and other necessities. Some States provide optional State supplemental payments to all persons qualifying for SSI benefits, while others may limit payments to certain State-defined SSI recipients, or may extend payments to persons who would be eligible for SSI except for excess income.

A significant number of States provide, for certain individuals, supplemental payments to the basic SSI payment to support selected community-based long-term care services. This is because the Federal SSI payment may be

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40/ This number includes persons receiving Federal SSI payments and/or Federally administered State supplementation.

insufficient to cover an individual's service needs which extend beyond room and board, such as non-medical supervision or other group living arrangements or personal care services. These services often include supervision of daily living or other protective housing services for the mentally retarded, chronically mentally ill, or the frail or confused elderly.

An analysis of optional State supplemental programs as of January 1985 shows that 35 States supported a diverse range of community-based long-term care services through their optional State supplementation programs. 41/ Payments are made to individuals to support their residence in a variety of housing arrangements such as adult foster care homes, domiciliary care homes, congregate care facilities, adult residential care homes, and shared homes for adults. In addition to providing payments for specialized housing arrangements, some States also provide supplemental payments to pay for personal care, home health and other home care services for eligible individuals.

B. Federal Research and Demonstration Initiatives

Over the last decade, the Federal Government has made a substantial investment in research and demonstration activities in community-based care by supporting a wide range of projects designed to test new ways of providing and coordinating long-term care services as well as to achieve costs savings in the provision of care. Federally funded demonstrations have been sponsored principally by the Department of Health and Human Services (DHHS), and within DHHS, by the Health Care Financing Administration (HCFA) and the Administration on Aging (AOA). In some cases, HCFA has waived Medicare or Medicaid service or

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41/ Information was compiled by CRS from The Supplemental Security Income Program for the Aged, Blind, and Disabled, Characteristics of State Assistance Programs for SSI Recipients, Social Security Administration, SSA Pub. No. 17-002. Jan. 1985.

eligibility requirements so that a fuller range of services may be provided to persons who would not ordinarily benefit under the existing programs.

With nursing home care representing a substantial portion of public and private expenditures for long-term care, most Federal research and demonstration efforts have had the following objectives: (1) to reduce the cost of long-term care by reducing inappropriate institutionalization and the demand for institutional care by persons who could otherwise be served through community-based services at less cost; (2) to test whether a carefully managed system of care would create more efficient use of existing services and deter unncessary institutionalization; and (3) to make available to clients a wider range of community-based services than previously existed. In order to accomplish these objectives, the projects developed case management systems to screen and assess persons judged "at risk" of institutional care in order to divert, where appropriate, persons to community-based care. In addition, case management systems were designed to improve the delivery of care to chronically ill persons with complex needs. Multidisciplinary teams (generally composed of medical, health, and social service professionals) were established to carry out the case management responsibilities.

Because the success of Federal demonstration projects was premised on the need to serve persons who could be diverted from nursing homes to less costly and more appropriate community care, effective client targeting strategies were of paramount importance. Projects used various methods to make decisions as to which prospective clients should be included in the demonstrations. Such methods range from the acceptance of persons whose needs, based on results of assessments of functional capacity, indicated a likelihood of nursing home entry, to acceptance of only persons who had already been determined eligible for nursing home placement based on specified nursing home preadmission screening procedures. It was believed that the demonstration projects could achieve cost savings only by serving those persons who could meet, or actually met, SNF or ICF level of care requirements, but who could be equally well cared for in the community by lower cost services.

Most of the projects have terminated as Federal demonstrations, but most have been viewed as precursors to the DHHS National Long-Term Care Channeling Demonstration Program begun in 1980 and completed in 1985. 42/ Because this demonstration was the most ambitious and extensive community-based long-term care effort to date, its results will be discussed separately below. However, some general remarks can be made about the themes which have emerged from these earlier demonstration initiatives.

At best, the demonstrations have shown mixed results in terms of overall costs savings, reductions in the use of institutional care, and effects on client functioning. Various reviews of the demonstrations conducted over the past decade have attempted to compare their respective findings and make general statements about their results. 43/ In general, many of these reviews have indicated that the demonstration findings do not support the view that cost savings can be achieved through the substitution of community-based long-term

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42/ It should also be pointed out that these demonstration initiatives also served as a model for the creation of the Medicaid Section 2176 home and community-based waiver program discussed earlier in this paper.

43/ Among the many reviews of these projects are the following: Stassen, Margaret and John Holahan, Long-Term Care Demonstration Projects: A Review of Recent Evaluations. Working Paper: 1227-2. The Urban Institute. Washington, D.C. February 1981; Berkeley Planning Associates, Evaluation of Coordinated Community-Oriented Long-Term Care Demonstration Projects. Prepared for the Health Care Financing Administration. Berkeley, California. May 1985. Burwell, Brian. Home and Community-Based Care Options under Medicaid. Affording Access to Quality Care: Strategies for Medicaid Cost Management. National Governors' Association Center for Policy Research. Washington, D.C. July 1986; and Doty, Pamela. Can Home and Community-Based Services Provide Lower Cost Alternatives to Nursing Homes? Working Paper. Health Care Financing Administration. Washington Washinton, D.C. December 1984.

care services for institutional care. In some cases, the community-based services offered to clients were found to be "add on" services, that is, additional benefits whose costs were not offset by reduced nursing home costs. In addition, there is some evidence that any costs savings that were achieved by diverting nursing home-bound clients to community care were offset by the additional costs incurred as a result of the case management and assessment process.

One of the principal reasons for these findings, however, is due to ineffective strategies for targeting community-based services on those persons who would actually have entered a nursing home without such services. Many of the projects served persons who were functionally disabled but who, in the long run, would not have entered a nursing home for a variety of reasons. Thus the projects were not found to have had any significant impact on reducing nursing home utilization. One exception to this has been demonstrated by a program in South Carolina which showed a substantial reduction in nursing home utilization though the implementation of a managed care system. This reduction has been attributed to the fact that the project accepted for community-based services only those clients who had already been determined to be in need of nursing home care through a State mandatory nursing home preadmission screening program. Although the demonstration was able to reduce nursing home utilization by successfully targeting a client group at high risk of institutionalization, it was able to only break even in terms of total costs. Consistent with the results of some of the other demonstrations, this break-even effect was attributed to the additional costs generated by the case management process and additional community-based services. 44/

44/ Burwell, p. 83; and Mathematica Policy Research, Inc. The Evaluation of the National Long-Term Care Channeling Demonstration: Final Report. Prepared for the Department of Health and Human Services. May 1986, pp. xix, 14.

In the area of the effects of the community care projects on client functioning, there are also mixed results. Some of the projects were able to demonstrate reduced mortality, and improved client outcomes in terms of functional or cognitive abilities. However, other projects were not able to support totally the view that a wider range of community care options would have overall positive benefits on the health and well-being of clients. In some cases this may be attributed to the fact that the projects were essentially dealing with a very frail and disabled group whose functional status is not easily improved through the initiation of these types of services. These findings may point up the dilemma of providing services to a chronically disabled group--because the needs of this group are so complex and of such a chronic nature, real improvement in client outcome may not in fact be an attainable goal.

Based on the weight of evidence emerging from the enormous amount of research which has been conducted on the effects of community-based care, many analysts have come to the conclusion that the promotion of such care as a cost-effective "alternative" to institutional care was based on a faulty premise. 45/ Analysts and service providers alike are increasingly recognizing that expanded community care services may in fact represent new services that result in additional expenditures for a functionally impaired population which is not at imminent risk of institutionalization but which nevertheless needs help to remain at home. Although there is some evidence showing that methods can be devised to target services effectively to a group who would otherwise be institutionalized, case management systems have not proved themselves on the basis of reducing costs.

45/ Weissert, William G. Seven Reasons Why It Is So Difficult to Make Community-Based Long-Term Care Cost Effective, Health Services Research, v. 20, no. 4. October 1985, p. 432.

1. National Long-Term Care Channeling Demonstration

In 1980, three units within the Department of Health and Human Services--the Health Care Financing Administration, the Administration on Aging, and the Office of the Assistant Secretary for Planning and Evaluation--initiated the National Long-Term Channeling Demonstration. This project was designed to test whether a carefully managed approach to the provision of community-based long-term care services to a frail elderly population living outside institutions could help control overall long-term care costs while maintaining or improving the well-being of its clients. This project has been the largest, and the most rigorously designed, demonstration undertaken to test the effectiveness of a case-managed approach to long-term care service provision. The program comprised 10 States and local sites, with about 6,326 frail elderly clients, and was designed with experimental and control groups.

The term "channeling" refers to organizational structures and systems which coordinate available long-term care resources and manage them effectively on behalf of functionally-impaired clients. Channeling was expected to achieve its effects principally by providing clients with case management services, and by substituting less costly community or informal services for more expensive institutional care. Services included a range of community care options such as home health aide, homemaker, nursing, and respite care. Service expenditures were subject to pre-established controls.

The program was devised to answer questions which previous Federal demonstrations had not totally answered, such as the cost of case management systems and how best to target community-based services on those who would otherwise be institutionalized. Other questions to be answered by the demonstration included: Does channeling reduce institutionalization and hospitalization? Is use of formal health and social services in the community increased? Do formal services substitute for services of families and friends? What impact does channeling have on public and private costs of long-term care, on longevity, improved health status, and overall client well-being?

The final results of the channeling demonstration do not support the argument for case-managed community-based services solely on the basis that they substitute for institutional care or that they can reduce the total costs of long-term care. However, the project did identify a range of unmet needs on the part of very frail older persons living in the community. Channeling clients were of advanced age (average age, 80 years), poor (average income of clients and spouses was $570 per month), and had major limitations in ability to conduct activities of daily living.

Major findings of the demonstration include the following:

- The increased costs of case management and expanded community services offered by the demonstration were not offset by reduced nursing home costs. As a result, costs increased overall for those persons receiving expanded services.
- Despite the frailty of the population, channeling did not identify a population who, without the services, would have entered a nursing home. Channeling did not substantially reduce nursing home utilization.
- Channeling did not affect longevity, hospital use, or use of physicians and other medical services.
- Channeling increased formal community service use. Service expenditures were highest for home health aide and homemaker/personal care services. Almost three-quarters of services dollars were spent for these services. This finding supports the prevalent view among social and health services providers that assistance with personal care and housekeeping represent the largest service need of the functionally imparied elderly and the one area which is inadequately supported by existing programs.
- Channeling did not have any major impact on the amount of caregiving already provided to clients by families and friends. (This finding is consistent with a wide body of gerontological literature indicating that initiation of formal services for impaired persons does not supplant the informal service provided by family and friends.)

- Channeling did not affect measures of client functioning, but did reduce unmet need for services, increased cients' confidence in receipt of care, and increased life satisfaction. 46/

While it is difficult to generalize about the application of the findings of the demonstration to other situations, the overall implications of the demonstration led to the following statement included by the evaluators in the final report:

> Expansion of the case management and community services beyond what already exists, then, must be justified on the basis not of cost savings but of benefits--increased in-home care, reduced unmet needs, and improved satisfaction with life among clients and the informal caregivers who bear most of the care burden." 47/

2. Social/Health Maintenance Organization Demonstration (S/HMOs)

In 1980, the Health Care Financing Administration, DHHS, and private foundations began funding the development, planning, and operation of the S/HMO concept for financing acute and long-term care services for an elderly population eligible for Medicare and/or Medicaid. The S/HMO concept builds upon and extends the health maintenance organization (HMO) model for financing acute, medical care services. Specifically, an HMO offers health insurance coverage for specific health care services on a pre-paid, capitation basis (the premium charge for enrollment) and either provides directly, or arranges to have provided, the health services covered under the insurance contract. The HMO is at risk for the costs of the services it covers; that is, it will experience some level of profit or loss on the basis of its ability to estimate in advance its revenues and the utilization and costs of services it provides.

46/ Mathematica Policy Research, Inc., pp. 76-77 and 169-176.

47/ Ibid., p. 185.

The success of conventional HMOs in managing acute medical care services and costs suggested the possibility of expanding the concept to include long-term care services to allow the elderly to begin to pool their risk for chronic care. Under the three-year HCFA S/HMO demonstration, four test sites across the country have assumed responsibility for financing and providing a full range of medical and long-term care services under a fixed budget which is determined in advance. The four S/HMO sites are the Kaiser Permanente Medical Program in Portland, Oregon; Metropolitan Jewish Geriatric Center in Brooklyn, New York; Ebenezer Society in Minneapolis, Minnesota; and Senior Care Action Network in Long-Beach, California. The four S/HMO sites serve an elderly population eligible for Medicare and/or Medicaid. Enrollees are to be a representative mix of people--from well to significantly impaired. Medicare, Medicaid, and private premiums will finance the services.

Long-term care services covered by S/HMOs include nursing home services, home health services, homemaker/home health aide services, personal care, adult day care, respite care, and home-delivered meals. Each S/HMO site has its own defined long-term care benefit. Because of limited experience with long-term care insurance and utilization, long-term care services are covered up to a maximum dollar amount per year and require a copayment. The limits range from $6,500 per year to $12,000. In addition, S/HMOs share with the Federal Government risks for plan losses in excess of certain dollar limits during the first 30 months of the demonstration and eventually assume full risk for the utilization and costs of covered services.

The four demonstration sites began providing services in 1985 and will continue to do so through June 1988. An independent contractor will evaluate all four sites. In general, the S/HMO demonstration is intended to provide information about the cost effectiveness of providing services in an integrated and managed system of care, its impact on the utilization of health and long-term care services by the elderly, and its effect on the quality of care available to the eligible population. Among the specific questions DHHS expects this demonstration to address are the following:

- ° Whether comprehensive long-term care insurance can be marketed to a significant number of elderly;
- ° What combination of benefits, eligibility criteria, premium and marketing techniques produce a viable long-term care insurance plan;
- ° Whether a consolidated, pre-paid system of acute and long-term care services can produce greater system savings than HMOs serving Medicare beneficiaries with acute care services only;
- ° Whether the new privately financed long-term care benefits will significantly reduce nursing home admissions and Medicaid "spend-down";
- ° Whether quality of care, service continuity and access can be improved by consolidating acute and long-term care in a single managed system; and
- ° Whether informal support (i.e., care provided by family members, friends and community volunteers) of chronically impaired elderly is enhanced in a pre-paid, risk-based, case-managed health care system offering both acute and long-term care services.

Prior to the S/HMOs actual operation, the Office of Management and Budget (OMB) opposed Medicare waivers required to initiate the demonstration. Citing the Medicare program's acute medical care orientation, OMB opposed in principle the use of Medicare funds for long-term care. 48/ OMB feared that the demonstration, by covering additional chronic care and social services, would increase consumer demand and pressure for support of long-term care through Medicare and other Federal programs. In addition, OMB argued that, if the consolidated prepaid system for acute and long-term care envisioned in the S/HMO demonstration did produce savings in acute hospital costs, Medicare would not save money,

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48/ Social Health Maintenance Organization Demonstrations: First Returns, National Health Policy Forum. Washington, D.C. Issue Brief 454. p. 6.

given the high occupancy rates in nursing homes and the large amount of community-based care provided informally by family and friends. Medicare would simply end up paying for long-term care through the capitated Medicare payment paid to S/HMOs, which is higher than the rate paid to other HMOs providing services to Medicare beneficiaries. Thus, Medicare funds would replace Federal/State funds used under the Medicaid program for long-term care, State/local funds supporting community programs, private out-of-pocket expenditures by individuals, and informal care. The result would be cost shifting, rather than savings to the Medicare program.

In the end, Congress overrode OMB objections and mandated the S/HMO demonstrations in the Deficit Reduction Act of 1984. The four S/HMO sites have been in operation for approximately 2 years and they are now beginning to analyze data on enrollment and marketing; utilization of hospitals, nursing homes, and other services; and cost of services.

At the end of 18 months, only one of the four S/HMO sites had reached the enrollment goal of 4,000 members. 49/ For the others, marketing the plan has been much more difficult than anticipated. This resulted in higher costs than expected. Hospital utilization at each of the S/HMO sites is significantly below local county rates. Both nursing home and home care utilization rates varies greatly across the sites. For the first 6 months of 1986, nursing home utilization varied across the four sites from 988 days per 1,000 enrollees per year to 2,530 days per 1,000 enrollees per year; and home care use varied from 5,282 hours per 1,000 enrollees per year to 40,073 hours per 1,000 enrollees per year. Chronic care costs for nursing home and home care varied from $19.92 per member per month to $36.21 per member per month during the first 6

49/ Social Health Maintenance Organization Demonstrations: First Returns, p. 7.

months of 1986.

Waivers for the S/HMO demonstration expire in 1988. HCFA has contracted with the Institute for Health Policy Studies of the University of California/ San Francisco to evaluate the S/HMO demonstration.

C. State Level Initiatives

The fragmentation and lack of coordination among major Federal programs which support long-term care services have provided the States with major implementation challenges. The Medicaid, Social Services Block Grant, and Older Americans Act programs all delegate administration and implementation responsibility to the States, and, in so doing, require the States to deal with problems inherent in the different goals of these programs, as well as their varying eligibility requirements, service benefits, and reimbursement policies. These implementation problems have also resulted from the fact that fragmentation at the Federal level has been mirrored in State administration, with major long-term care programs being administered by different State agencies.

Many States have responded to these challenges by enacting legislation and/or creating initiatives to reorganize and restructure benefits offered through the Federal programs, and to consolidate the administration of various long-term care programs in a single State agency.

State initiatives to alter and coordinate their long-term care policies have been inspired, in part, by federally sponsored demonstration projects begun in the 1970s. Despite the mixed and rather negative results of the federally-sponsored demonstration efforts with respect to the impact of expanded community-based care on the costs of care, the directions established by the demonstrations have had widespread influence on State program development. For example, demonstrations funded under Medicaid and Medicare waiver authorities and the Older Americans Act research and demonstration authorities have served as models for State-mandated case management systems and nursing home preadmission screening programs. Many States have, through the creative use of Medicaid, Social Services Block Grant, and Older Americans Act funds, created major system-wide changes in the way in which community care is organized and delivered. In addition, demonstration initiatives have also served as a testing ground for new community-based service models. For example, adult day care demonstrations which took place during the 1970s encouraged State and local agencies to merge existing health and social service funds available under Medicaid, title XX, and the Older Americans Act to create the now more than 1000 adult day care programs in existence.

Certain parallel activities have been initiated by States without the benefit of Federal demonstration funds and without any changes in Federal legislation. A number of States have attempted to reduce the need for institutional care by redirecting existing Federal program funds or by using existing Federal and complementary State funds in new ways. For example, the Virginia State Medicaid agency operates a nursing home pre-admission screening program through local public health departments for persons likely to be admitted to a nursing home but whose needs could be addressed through community-based services. The Massachusetts State agency on aging has established community-based organizations to manage certain key home care services for older persons through creative use of title III Older Americans Act funds and State funds. The Utah State agency on aging has established a program to identify persons at risk of being institutionalized and has developed alternative community-based service plans using personnel of the State's area agencies on aging network.

The objective of reducing institutional care costs and diverting potential users to other forms of care may have been the original impetus behind much of State efforts to alter long-term care systems. However, as evidence from demonstrations has proved to be increasingly less optimistic about cost-savings, long-term care systems development has become a priority of State legislatures for other reasons, such as the growth and aging of the elderly population and the necessity to plan for the future, and the desire of State legislators and planners to be responsive to the preferences of the elderly for community-based care over care in institutional settings.

Some of the themes evidenced in State level initiatives include the following:

- Control of institutional access through screening/assessment procedures. Many States have initiated screening and comprehensive medical and social assessment procedures of those "at risk" of long-term care services in order to ascertain the most effective and least costly care option, given the client's needs. Such screening and assessment procedures are generally applied to persons about to enter a long-term care facility. A review of State Medicaid programs in 1981 showed that 28 States had mandatory preadmission screening programs for Medicaid patients prior to nursing home admission. 50/
- Reorganizing access to community services. Some States have devised projects aimed at reorganizing access to community services by providing case management services or "gateway" procedures for clients. This concept has been developed to overcome problems associated with multiple providers and duplication of services that have resulted in client confusion as to source of care and unnecesary administrative costs among agencies. The availability of Medicaid funds under the 2176 home and community-based service waiver program has recently spurred the development of many more case management systems but perhaps not on a statewide basis.
- Consolidation of State administrative and funding responsibilities. Some States have combined authority for the administration and funding for all, or most, long-term care services under one

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50/ Knowlton, Jackson, Steven Clauser, and James Fatula. Nursing Home Pre-Admission Screening: A Review of State Programs. Health Care Financing Review, v. 3, no. 3, March 1982. p. 78.

State agency. Such action is designed to improve coordination and management of care, and to overcome fragmentation resulting from diverse requirements under various Federal programs.

- Cost control mechanisms. Some States have eliminated the uncertainty of whether community care will exceed institutional care costs by pre-establishing upper cost limits on such care; for example, community care may be provided only when such care does not cost more than a certain percentage of institutional care. An example of this concept is contained in New York's Nursing Home Without Walls program. This cost control concept was incorporated into the National Long-Term Care Channeling Demonstration program and is a basic element of the Medicaid 2176 home and community-based service waiver program.

- Tax incentives for dependent care. Many States permit favorable tax treatment for families or other caretakers who care for dependent older persons. According to a survey of the National Association of State Units on Aging, 27 States and the District of Columbia have adopted some form of dependent care tax credits, generally designed to assist in the care of dependents by adults who are working or seeking work. Of these 27 States, five have enacted tax provisions specifically designed to assist caregivers with the expenses of caring for older persons. These States are Arizona, Idaho, Iowa, North Carolina, and Oregon. 51/

51/ National Association of State Units on Aging. State Tax Policy Options for the Elderly: A Guide for Aging Advocates. May 1985. Washington, D.C. p. 46-47.

IV. PRIVATE SECTOR APPROACHES TO FINANCING AND DELIVERY OF LONG-TERM CARE

Budgetary constraints resulting from growing Federal deficits and increasing expenditures required under various entitlement programs which currently finance long-term care have served to shift the focus of the long-term care debate from reform of Federal programs to consideration of private sector initiatives which might relieve fiscal pressures on public programs and which at the same time may improve the elderly's ability to finance long-term care. Observers have also noted that the decline in the ratio of workers to retirees and the growth in numbers of the very oldest segment of the population may have a marked impact on the ability of public programs to support long-term care in the future. In addition, others point out that the economic status of future generations of the elderly may improve significantly and that they will therefore be able to pay for a larger portion of the cost of certain long-term care services.

The improvement in the economic status of certain groups of elderly may lead policy-makers to target public sector long-term care programs on the most needy income categories of elderly, while at the same time to encourage various private sector financing approaches which could assure greater protection against the cost of long-term care services for those who are relatively better off. However, at the current time, most elderly do not have the resources to pay for the catastrophic expenditures associated with certain long-term care services over an extended period of time. For many, depletion of assets and income for the cost of care and subsequent Medicaid eligibility is the only remedy.

A number of private sector approaches have recently been suggested as potentially feasible alternatives for financing long-term care services. These range from ways to pool risks associated with long-term care need through private insurance and life care communities to conversion of an elderly homeowner's equity into a source of funds to pay for care. A discussion of these approaches and their feasibility for financing long-term care follows. It should be noted that these private sector alternatives may have only limited applicability for the large number of elderly who are poor or may be poor in the future. Another method of risk pooling, the social/health maintenance organization, was discussed above in the section on public financing and delivery. This report does not discuss still other options suggested as feasible alternatives for enhancing the elderly's ability to finance long-term care expenses, including the various tax code modifications proposed to assist families to continue providing long-term care services.

A. Private Health Insurance Coverage for Long-Term Care

Among the private sector approaches receiving increased attention recently as a potential alternative for financing long-term care services is private health insurance. This alternative has been suggested not only because of growing fiscal constraints on public program expenditures, but more basically because private insurance coverage is currently available for a wide variety of health care services and catastrophic illness. Private insurance is generally not available, however, for long-term care services or the catastrophic costs associated with long-term care.

Expenditures for long-term services, and especially for nursing home care, not only strain the budgets of public programs; they are also a burden on private resources. In 1985, total national nursing home expenditures of $35.2

billion were financed about equally by public programs and private sources of payment. Public programs financed $16.5 billion of the total, and private sources $18.7 billion. Of total private spending for nursing home care in 1985, less than two percent was paid by private insurance coverage. Ninety-seven percent of the total private spending for nursing home care was paid directly by the consumer out-of-pocket. The average annual cost of nursing home care is in the range of $20,000 to $25,000 per year, representing a catastrophic expenditure beyond the financial reach of most elderly. 52/ In fact, one study found nursing home cost to be the primary catastrophic expense of elderly persons with out-of-pocket expenses over $2,000 a year. For these individuals, nursing home costs accounted for over 80 percent of these costs. 53/

In addition, private insurance coverage has been viewed as a feasible alternative because of general interest among the elderly population in purchasing private insurance to supplement their Medicare benefits. Nearly two-thirds of the elderly currently purchase such "medigap" policies. While these policies generally pay only certain deductible and coinsurance amounts for which Medicare beneficiaries are liable and do not cover long-term care, the widespread interest of the elderly in this broader coverage suggests to some observers that a market for long-term care coverage can and does exist.

Furthermore, evidence indicates that the elderly will have higher incomes and assets in the future which will enable them to afford premiums for coverage. One study has estimated that given future income levels and growth of pensions, approximately 93 percent of all married couples at age 65 and almost 60 percent

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52/ Doty, Liu, and Wiener, p. 74.

53/ Rice, Thomas, and Jon Gabel. Protecting the Elderly Against High Health Care Costs. Health Affairs, v. 5, no. 3, fall 1986. p. 17.

of all single persons at that age would be able to purchase long-term care insurance with less than five percent of their cash income by the year 2005. 54/

Currently, relatively few insurance companies (surveys have found 12 to 38) write long-term care insurance policies which are substantially more comprehensive than standard medigap policies and which go beyond restrictive Medicare definitions for skilled nursing care to include intermediate and custodial care. Surveys estimate that these policies cover from 50,000 to 150,000 persons. 55/ Premiums for most of the available policies increase with age of initial purchase. The plans vary by length of time benefits are covered, waiting periods before benefits can begin, and the conditions upon which benefits will be paid. Most plans provide indemnity benefits, paying a fixed amount for each day of covered service, thereby limiting the insurers' liability. In addition, most have utilization controls to further limit an insurer's liability and to protect the insurer against unnecessary utilization of benefits. These include medical screens and physical examinations for utilization of benefits, preexisting condition restrictions, prior hospitalization requirements, exclusion of mental and nervous disorders, and renewability limitations. Home care benefits, especially those related to custodial or personal care, are included in even fewer long-term care insurance policies. Often plans that cover any home care at all require a prior stay in a hospital or skilled nursing facility

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54/ Private Financing of Long-Term Care: Current Methods and Resources. ICF, Inc., Final Report Submitted to the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, Phase I, Jan. 1984. p. 79.

55/ Private Financing of Long-Term Care, p. 12. For a review of plans, see also, Meiners, Mark. The State of the Art in Long-Term Care Insurance. Long-Term Care Financing and Delivery Systems: Exploring Some Alternatives. Conference Proceedings. Health Care Financing Administration, Department of Health and Human Services, Jan. 24, 1985. Also, The State of Private Long-Term Care Insurance: Results from a National Survey. Health Insurance Association of America. Research and Statistical Bulletin, no. 5-86, Nov. 25, 1986.

in order to reduce the large potential demand for home care among the majority of the covered population that has never been institutionalized. 56/

A number of barriers have been cited as impediments to the development of meaningful long-term care insurance policies. 57/ Traditionally, insurers have been concerned about the potential for adverse selection in long-term care insurance, where only persons more likely to need care actually buy insurance. In addition, insurers point to the problem of the induced demand for services that can be expected to be generated by the availability of new long-term care insurance. With induced demand, sometimes also referred to as moral hazard, individuals decide to use more services because they have insurance and/or will shift from non-paid to paid providers for their care. This is especially critical in long-term care with 60 to 80 percent of disabled or impaired persons receiving home care services from family or friends who are not compensated.

Still other factors are mentioned as problems inhibiting the development of long-term care policies. Many long-term care services that are felt to be critical in enabling frail elderly persons to remain in their homes are custodial, non-medical services. Traditionally these services, such as personal care, homemaker, and nutritional services are considered noninsurable because of difficulty in confining eligibility to a limited number of people. In addition, observers have noted that, given the nature of many chronic conditions, many people who need long-term care will need it for the remainder of their lives, resulting in an open-ended liability for the insurance company. Moreover,

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56/ Increasing Private Financing of Long-Term Care: Opportunities for Collaborative Action. SRI International, Aug. 1985. p. 14.

57/ Long-Term Care: The Challenge to Society. Health Insurance Association of America, 1984.

evidence exists that the elderly do not understand their insurance coverage or their potential need for long-term care. As a result, they do not demand coverage. Some elderly believe they are already adequately covered for such services under Medicare while others think they have coverage for long-term care with their purchase of a medigap policy. For example, a 1985 survey conducted by the American Association of Retired Persons (AARP) found that 79 percent of the elderly believe that Medicare will cover most of the cost of nursing home care services. About one-third (35 percent) mistakenly believed that their medigap policies included extended nursing home coverage.

According to a study of the Health Insurance Association of America (HIAA), one of the most significant barriers to the development of private insurance options is the major role played by Medicaid in financing long-term care and especially nursing home services. According to the HIAA report, Long-Term Care: The Challenge to Society, Medicaid is already viewed by many as a national coverage program for long-term nursing home care, used by far more than the low income population usually thought of as Medicaid's primary clients. In addition, the ability of individuals to plan for the transfer of assets expands the number of persons eligible for long-term care benefits under the program. According to HIAA's report, public programs are viewed as a safety net providing protection against the catastrophic costs of care. The report calls for reduced Medicaid involvement in financing nursing home care so that fewer middle income individuals can view the program as a viable option for their long-term care needs.

As noted above, the number of long-term care insurance policies providing meaningful protection for the at-risk elderly population is very limited. However, recent research suggests that many of the barriers that are commonly thought to preclude the development of long-term care insurance are subject to resolution by careful policy specification, including limitations on number of days covered, waiting periods before benefits can begin, and maximum amounts payable. 58/ In addition, research has found that significant reductions in annual premium rates could be offered if persons were encouraged to buy at younger ages and to accept longer periods before coverage begins and shorter length of coverage for benefits. 59/ Others have suggested that allowing families to purchase protection for their elderly parents could make long-term care insurance a more feasible option. Adding adult children, who have a much lower risk of incurring long-term care expenses for themselves, to the pool of the insured could expand premium collections and at the same time make a policy more affordable. The adult children could pay for the premiums on behalf of their elderly relatives as well as themselves, but presumably they would not begin to make claims for long-term care services on their own behalf until some future time.

Observers have noted that the employee benefits market has the potential for expanding the long-term care insurance pool in ways suggested above. In addition, employer-based coverage could increase the affordability of long-term care insurance, since currently a significant portion of the long-term care insurance premium is associated with the expense of marketing and underwriting individual policies. Group coverage for long-term care has not been available until recently. In December, 1986, the Travelers Insurance Company announced a long-term care insurance product that will be available to employers with 10,000 or more eligible workers. Coverage would be available to both active and retired employees and their spouses, and if the sponsoring employer so

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58/ Meiners, The Case for Long-Term Care Insurance.

59/ Meiners, Mark and Gordon Trapnell. Long-Term Care Insurance: Premium Estimates for Prototype Policies. Medical Care, v. 22, no. 10, Oct. 1984.

chose, to parents of active employees and their spouses as well.

In addition, the Office of Personnel Management announced in January, 1987 the intention of adding a new long-term care option to the life insurance program currently available to Federal employees. Under the proposal, Federal employees who have been covered under the life-insurance program for at least 10 years and who are at least 50 years old could convert a portion of their basic insurance to long-term care protection. As presently conceived, Federal employees could voluntarily elect to pay an additional long-term care premium that would entitle the employee to 3 years of nursing home and home health benefits paid at a fixed amount.

What is unclear at present is the extent to which private insurance companies will expand and broaden their offerings of long-term care insurance products in the future. A recent survey by the HIAA found a number of companies entering the market within the past year, others developing new products or refining old ones, and still others developing longterm care products for the first time. 60/ However, this same survey found that two companies, including one with extensive years of experience, recently reduced their sales of long-term care insurance products. One company did not receive the premium rate increases it requested from a State insurance commission and subsequently stopped writing new policies. The other company, with a large share of the market, found it necessary to redesign its policy to reduce adverse selection. It also limited the number of States in which it sold the revised policy and implemented rate increases in all States where it had the original policies in force.

In November, 1986, Secretary Otis Bowen transmitted to the President the Department of Health and Human Services' report on Catastrophic Illness Expense,

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60/ The State of Private Long-Term Care Insurance: Results from a National Survey. Health Insurance Association of America. Research and Statistical Bulletin, no. 5-86, Nov. 25, 1986. pp. 3,4.

requested by the President earlier in the year. This report addresses the issue of need to stimulate the supply of private long-term care insurance options and to broaden the market for such policies. The report recommends encouraging the development of the private market for long-term care insurance in three ways: (1) establish a 50 percent refundable tax credit for long-term care insurance premiums for persons over age 55, up to an annual maximum of $100; (2) provide the same favorable tax treatment for long-term care insurance reserves as is now the case for life insurance; and (3) remove certain barriers included in the Deficit Reduction Act of 1984 to prefunding long-term care benefits provided by employers to retirees. It is unclear how Congress will respond to these recommendations of Secretary Bowen's report. In the meantime, the Task Force on Long-Term Health Care Policies, established in DHHS by the Consolidated Omnibus Budget Reconciliation Act of 1985, is meeting to make recommendations on (1) the development of the long-term care insurance market, (2) assuring access to information by consumers; (3) limiting marketing and agent abuses; and (4) assuring reasonable value of long-term care policies. The Task Force is required to report to the Secretary and Congress on its recommendations by October, 1987.

Non-traditional health insurance alternatives have also been advanced as viable options for long-term care financing. Some have suggested that long-term care services can be controlled only in a managed care system, such as an HMO, and it appears that a limited number of HMOs include among the benefits they cover for non-Medicare enrollees certain medically necessary long-term care types of services, such as skilled home health care, SNF, and hospice care. In addition, the social/HMO demonstration project described above will provide information about the feasibility of this approach. In addition, some have pointed to tax-preferred cash accumulation plans, such as individual retirement accounts (IRAs) reserved for long-term care costs, as possible approaches to be considered. Some have suggested that cash accumulation instruments are perhaps most appropriate when there is a very high probability that a person will need a service at some point in time and when the costs of the service are not beyond the means of a person's life-time savings capacity. 61/ Home care services might be a more likely candidate for this form of financing than a long nursing home stay.

It should be noted that while insurers remain reluctant to enter the market for long-term care insurance, States, faced with mounting Medicaid nursing home expenditures, are expressing increasing interest in having such coverage more widely available. According to HIAA, legislatures in a number of States have introduced bills that would mandate long-term care insurance coverage for group policies sold in the State. 62/ In addition, during 1986 six States passed laws that focus on minimum standards, conditions, and disclosures for long-term care insurance policies. At least ten other States are examining long-term care insurance, primarily as part of legislatively directed studies. Also, it should be noted that the National Association of Insurance Commissioners issued a report in December, 1986, with a proposed model bill for State legislatures to consider when they decide to regulate long-term care insurance policies at the State level.

61/ Increasing Private Financing of Long-Term Care: Opportunities for Collaborative Action. SRI International, Aug. 1985. p. 10.

62/ Health Care Viewpoint. Health Insurance Association of America, fall, 1986. p. 4.

B. Life Care or Continuing Care Retirement Communities 63/

One long-term care living arrangement available for financing long-term care services for a limited but potentially growing number of elderly persons is the life care community. Life care, also called continuing care retirement communities, are organizations, usually situated in a campus-like setting, established to provide housing, meals, housekeeping, and social activities, to older persons for the duration of their lives. In addition to these basic services, life care communities provide a range of long-term care services offered on the grounds of the facility.

The distinguishing characteristic about life care communities is the guarantee that residents will be provided with a range of services as long as they are residents of the community. Rights and obligations of the resident and the community are defined under the terms of a life care contract. The life care contract sets forth the services to be received by the resident in exchange for financial payments, including an entrance fee and monthly charges. Because the life care contract is intended to provide financial protection against the future cost of long-term care services for each resident, it may be viewed in part as a form of insurance.

Long-term care services provided in a life care community may include skilled and intermediate nursing home care, personal care, and other health care services such as home nursing, and physical, occupational, or speech therapy. Life care communities may differ in the amount of pre-paid nursing care offered under the terms of the contract. Acute care and hospital care are not provided, and some communities may require the resident to share in

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63/ Portions of this section were drawn from CRS Report 85-1127 EPW, Life Care Communities: Description and Current Issues, by Evelyn Howard, December 23, 1985.

the cost of health/long-term care services they receive from the community. Residents continue to use Medicare and/or private insurance plans to cover the costs of acute and long-term care services.

Generally residents who enter life care communities are relatively healthy but as their health/long-term care needs increase, they are provided with increased services as stipulated under the terms of the life care contract.

The number of life care communities is currently very small. Two major studies of such communities have provided a range of estimates of the numbers of communities--from about 300 to 600, depending upon the definition used. It is estimated that there are at least 90,000 persons residing in nearly 300 such facilities. 64/ According to the AARP, the number of life care communities doubled in the past 10 years and is expected to more than double in this decade. 65/ Although most of the life care facilities in existence are operated by private, non-profit organizations, and some are affiliated with religious organizations (primarily Protestant), there has been increasing interest on the part of corporations in developing such facilities.

In order to gain access to a life care facility, a resident is required to pay a lump sum entrance fee with monthly payments thereafter which are usually adjusted for inflation. Fees are generally based on the size and type of living unit (e.g., studio, one-, two-, or three-bedroom apartment). In addition, fees are based on some actuarial assumptions, such as life expectancy rates and projected future health care needs.

64/ These estimates are from the following sources. A 1984 study, Continuing Care Retirement Communities: An Empirical, Financial and Legal Analysis [by] Howard E. Winklevoss and Alwyn V. Powell estimated that there were about 275 life care communities serving about 90,000 elderly persons. Another survey of the life care industry in 1984 by Laventhol and Horwath, estimated about 600 communities.

65/ American Association of Retired Persons. National Continuing Care Directory, edited by Ann Trueblood Raper. Washington, D.C., 1984. p. 5.

Some analysts have observed that the entrance and monthly fees may make the life care or retirement community option inaccessible to large numbers of elderly. A 1985 study retirement communities by Laventhol and Horwath found that the range of entrance fees was from $11,000 to over $100,000 depending upon a number of factors, such as location, size of living unit, and age of facility. 66/ Some analysts, however, dispute the claim that life care is only for the relatively well-off elderly. A study of communities by Winklevoss and Powell indicates that although the range of entrance fees is wide, the average fee is moderate. According to this survey, the average entrance fee for 275 communities in 1981 was about $35,000 for one person and $39,000 for two persons, with average monthly payments of $562 and $815, respectively. 67/

Analysts have pointed out that the life care concept can be viewed as a form of long-term care insurance in that residents pool their resources and share the risk of future costs of long-term care services. A portion of the entrance fees and monthly fees paid by all residents is used by the community to pay for the health and long-term care costs of a small number of residents needing more extensive care at any given time. Because only a small number of residents would be expected to need intensive services at a given time, the fees could be considered like insurance premiums paid by the entire group but used by only a small group at a given time. In some cases, participation in a life care community may be viewed as a form of income redistribution when some portion of the fees paid by all residents are used to subsidize the costs of residents who can no longer afford to pay for their own care. 68/

66/ Laventhol and Horwath. Lifecare Retirement Center Industry, 1985, Philadelphia, Pa., p. 16-17. The retirement care facilities used in the study varied greatly in terms of amount of nursing care offered and fee structure used.

67/ Winklevoss and Powell, p. 12.

68/ Winklevoss and Powell, p. 13.

Supporters of life care communities indicate that there are a number of advantages in this mode of long-term care. Life care communities offer continuous, and in large part, pre-paid health and supportive care in a protected setting with personal and financial protection against the costs of future health/long-term care needs. Residence in such a community may offer increased opportunities for residents to maintain their relatively healthy status upon entry since professional oversight is available on a regular basis, as compared to completely independent living in the community where older persons may not actively seek health promotion opportunities. Residence in a protective community which offers a range of care situations may allay the fears that many elderly face of making a sharp transition from their homes to permanent residence in a nursing home when they become suddenly disabled. The pooling of health and long-term care risks may reduce the uncertainties of future costs of care, and the care provided under the terms of the life care contract can supplement coverage of acute care provided by Medicare and private health insurance.

While life care communities may offer an option to some elderly, and even increasing numbers in the decades to come, they may not be able to serve a large proportion of the elderly population in general. Life care is not an option for the poor elderly or those with relatively intense pre-existing health/long-term care needs. The idea of signing over a large portion of accumulated assets in one lump sum to an organization in return for protection against future costs may not be acceptable to large numbers of elderly persons. Turning over assets in such a way may eliminate inheritances for children.

While some elderly may not be able to afford the relatively hefty entrance fees, analysts have pointed out that the equity older persons have in their homes may be employed for this purpose. The proportion of elderly persons owning their homes is large and they have substantial equity as a result. Of the 18.2 million households headed by older persons in 1984, 73 percent were owners. The mean value of equity in homes held by the elderly in 1984 was $55,000. 69/ More than 80 percent of the elderly have paid off mortgages. 70/ One study points out that the high level of net home equity held by the elderly is not held only by those with higher income. About 65 percent of all elderly poor are homeowners, with 22 percent of the poor having more than $50,000 in net home equity. 71/ Other analysts indicate that because future generations of elderly will be better off than those of the past, the elderly may be in a more advantaged position to afford this kind of care in the future. Inflation adjusted retirement income under Social Security combined with private pensions and with IRA income may make the inflation adjusted monthly fees associated with life care communities payable by increased numbers of future generations of elderly.

Experience with life care communities is limited as are data about their effect on costs of organizing an integrated, pre-paid approach to long-term care service delivery. While it has offered an attractive option to a small number of elderly persons in the past, there have been problems. Some communities have experienced financial problems due in part to poor actuarial assumptions about the projected longevity of residents and their future health care

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69/ U.S. Bureau of the Census. Current Population Reports. Series P-70, no. 7. Household Wealth and Asset Ownership: 1984. U.S. Gov't Print., Off., Washington, D.C., July 1986.

70/ Jacobs, Bruce. The National Potential of Home Equity Commission. The Gerontologist. v. 26, no. 5., October 1986. p. 496.

71/ Jacobs, Bruce and William Weissert. Home Equity Financing of Long-Term Care for the Elderly. Long Term Care Financing and Delivery Systems: Exploring Some Alternatives. Conference Proceedings. Health Care Financing Administration, Department of Health and Human Services. Washington, D.C. Jan. 1984. p. 83.

needs, resulting in depletion of funds to cover costs. In view of these considerations, there has been interest on the part of Federal and State officials in more oversight and regulation over the development of these facilities in the interest of consumer protection. 72/ According to a DHHS study, 16 States have enacted legislation to regulate the life care industry. 73/

C. Home Equity Conversion

The search for alternative approaches to financing long-term care services has led some researchers to analyze the feasibility of using the single largest asset most older persons have--the equity in their home. As pointed out in the previous section, about 73 percent of elderly headed households are owner occupied. The overall homeownership equity held by elderly is substantial. It is estimated that the total equity held by elderly homeowners is about $700 billion. 74/ Some observers believe that, if converted into a source of cash, homeowner equity could be a tangible means of financing long-term care services for some elderly who are "house rich, but cash poor."

72/ In 1978, the Federal Trade Commission began investigating management and marketing practices of some life care communities. See U.S. Senate Special Community on Aging, Life Care Communities: Promises and Problems. S. Hrg. 98-276, Washington, D.C. May 25, 1983.

73/ U. S. Department of Health and Human Services, Health Resources and Services Administration. Life Care Centers: An Alternative Delivery System for the Elderly. Washington, D.C., June 1986. p. 6.

74/ U.S. Department of Health and Human Services. Catastrophic Illness Expenses. Report to the President, November 1986. p. 80-81. See U.S. Congress. Senate. Special Committee on Aging. House Select Committee on Aging. Home Equity Conversion. Issues and Options for the Elderly Homeowner. Testimony of Kenneth Beirne, General Deputy Assistant Secretary for Policy Development and Research, Department of Housing and Urban Development. Briefing Document. House Pub. 99-513. Jan. 28, 1985. Washington, D.C. p. 58.

There are two major types of mortgage instruments which may be used to convert equity into income: reverse mortgages, and sale/leaseback contracts. [75]

- Under the reverse mortgage, the homeowner enters into a loan agreement with a financial institution which uses the property as security for the loan. The older person retains ownership rights to the home, receives a regular stream of income based on the loan, and accumulates a debt on the loan amount. The loan may be calculated so as not to exceed some proportion of the property value. When the loan becomes due the owner has the option to convert the debt into a regular first or second mortgage, to sell the property to pay off the debt, or obtain a new reverse mortgage. The time period for the reverse mortagage may range from 7-10 years or for the remainder of the individual's lifetime depending upon the terms of the contract.
- Under the sale/leaseback contract, the homeowner sells the equity in the home but retains the right to reside there, usually for life. The buyer of the equity provides the elderly homeowner with a down payment and pays the balance in regular monthly installments. The seller, then, in effect becomes a renter of the home which he/she formally owned.

In one extensive analysis of the potential for application of homeowner equity toward payment of long-term care expenses, researchers concluded that there is evidence that a large proportion of older persons could use some of their home equity to finance long-term care needs. This analysis showed that about one-third to one-half of all elderly homeowners at high risk of need for home care could finance a portion of home care needs out of homeowner equity. The analysis also found that homeowner equity could be used to pay for long-term care insurance premiums as well as for nursing home care. [76] Another analysis which reviewed the potential for use of homeowner equity to purchase private long-term care insurance showed that home equity conversion could increase the ability of some elderly homeowners to pay for long-term care insurance, but concluded that reverse annuity mortgages and sale/leaseback arrangements do not easily provide for long-term care financing. Since these arrangements provide for payments to individuals for longer periods of time than usually needed to finance certain long-term care expenses, they may not have wide application for certain expenses requiring lump sums of cash over a short period of time. This report suggested that home equity conversion could be more useful if financial institutions permitted owners to use their homes as lines of credit, as necessary, to pay for long-term care expenses.77/

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[75] Reverse mortgages are also sometimes described as "reverse annuity mortgages" or "loan plans." For further information, see Converting Home Equity Into Income for the Elderly: Issues and Options, by B. Ellington Foote, CRS Report No. 84-42. Apr. 5, 1984.

[76] Jacobs, Bruce and William Weissert. Home Equity Financing of Long-Term Care for the Elderly. Long Term Care Financing and Delivery Systems: Exploring Some Alternatives, Conference Proceedings, Health Care Financing Administration, Department of Health and Human Services. Washington, D.C. Jan. 24, 1984. It should be noted that these findings were based on a model of probability of using home equity for this purpose, not on actual experience as to application of equity toward long-term care expenses.

While the idea of using home equity for payments of on-going expenses of the elderly has appeared in the literature for a number of years, the actual number of home equity conversion contracts is very limited (estimates range from 300 to 400 contracts at most). Lenders in only a handful of States have offered home equity loans and these loans may not be made on a regular basis. 78/ Therefore, the actual experience is relatively meager and its specific application to long-term care may be tentative. Recent changes in the Federal tax code may encourage the development of the use of home equity for purposes defined by elderly homeowners.

77/ ICF Incorporated. Private Financing of Long-Term Care: Current Methods and Resources. Phase II. Submitted to the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, Jan. 1985. pp. 25-26.

78/ According to an information paper of the U.S. Senate Special Committee on Aging, lenders in the following States have offered loans: Arizona, Califoria, Maine, Minnesota, New Jersey, Ohio, Pennsylvania, and Wisconsin. See U.S. Congress. Senate. Special Committee on Aging. Turning Home Equity into Income for Older Homeowners: An Information Paper. S. Rept. 98-216. July 1984. p. 12.

Thus far, there appears to be a lack of consumer demand. A number of obstacles have been cited as barriers to the future development of these arrangements. Many of the elderly may be reluctant to enter into these agreements because they wish to pass on some inheritance to their heirs. Also, even if this strategy were more widely available, some question whether the elderly would actually use the funds to pay for long-term care services. Other elderly may not participate because they may feel that services available from public sources will be decreased if they use their home equity. Also, they may feel that if they outlive their equity they may be forced to move. A number of other issues have been raised, including possible depreciation of homes, and concern that the elderly would not receive fair market value for their homes or that the lenders may default on the loans. These issues would require consumer protection measures.

There has been reluctance on the part of financial institutions to offer these instruments, particularly due to the current lack of mortgage insurance on the loans. Also, if the elderly homeowner lives beyond his/her equity, lending institutions may lose money because they may be reluctant to evict an elderly homeowner when the equity is exhausted. Finally, institutions may not want to enter into agreements in cases where the home is not expected to appreciate.

Other issues with respect to the tax implications of home equity conversions remain to be resolved. According to the Department of Housing and Urban Development (HUD), the status of sale/leaseback arrangements under the Internal Revenue Services (IRS) code is unclear. Questions in need of resolution include the right of the seller-lessee to take advantage of the one-time homeowner capital gains exclusion, and the ability of the purchaser-lessor to depreciate the rental property like other rental property. 79/

While home equity conversion is not extensively available, such arrangements may be attractive to some elderly for targeted long-term care expenses if the market became sufficiently developed and loans were devised to be responsive to individual needs. Conversion of home equity into cash to be applied toward the down payment for life care facilities was discussed above. Conversion of home equity to remain in one's own home may be more attractive in the long run than using equity to finance a life care facility down payment. Because this option allows house rich, but cash poor elderly to remain in their own homes by drawing upon a ready flow of funds, it may ultimately appeal to many more persons than life care. It may particularly appeal to those without heirs who would benefit from the sale of the home upon the death of the homeowner. Advocates of this concept indicate that this strategy could generate a significant amount of funds which, if directed toward payment of long-term care services currently paid for by public sector programs, could reduce pressure on these programs.

79/ U.S. Congress. Senate Special Committee on Aging and House Select Committee on Aging, Home Equity Conversion: Issues and Options for the Elderly Homeowner. Testimony of Kenneth Beirne, p. 59.

V. ISSUES TO BE CONSIDERED IN FUTURE PROSPECTS FOR LONG-TERM CARE

In the past, debate on Federal long-term care policy has focused on a number of issues which policy-makers still seek to resolve: how to offer more consistent and adequate protection for long-term care expenses; how to strike a balance between institutional and community-based care; and whether community-based care is more cost-effective than institutional care. Whereas in the past these issues were discussed principally in the context of proposals to reform Federal programs of support for long-term care, today questions arising from these issues are applied as well to a new dimension of the debate: the extent to which private sector alternatives, such as private insurance, life care communities, and home equity conversion, can improve the elderly's ability to finance the long-term care services they need and want.

Most recently these approaches have been discussed in the context of the recently published DHHS report to the President on catastrophic illness expenses. Largely as a result of this report, there is renewed interest in the catastrophic expenses often associated with long-term care and the financial risk elderly persons face when they need long-term care services. However, it appears at present that Congress will defer action on catastrophic long-term care expenses and confine action to catastrophic coverage for certain Medicare-covered services.

Although the debate on the financing of long-term care may have widened to include private sector approaches, it is also likely that reform of current Federal benefit programs will continue to be an area of consideration due to the large Federal investment in long-term care as well as the large numbers of elderly who depend upon these programs for assistance. Some of the questions to be reviewed in the future may include the following:

- What are appropriate roles for public programs and private sector options to play in the financing of long-term care? Can comprehensive long-term care coverage be provided without public mandate and/or subsidy? For example, the health insurance industry has been reluctant to offer comprehensive long-term care coverage, suggesting that adverse selection and induced demand for services will result in an insufficient pool of premium income to cover anticipated expenditures. What measures are necessary to obtain an adequate population base for long-term care insurance coverage that is affordable? Is some kind of public mandate required? Can certain tax incentives stimulate the development of an adequate private market for insurance?

- Even if the economic status of future generations of the elderly improves significantly, it is likely that they will continue to have differentiated needs and abilities to pay for long-term care. How should public programs and private sector options respond to the needs of a diverse population? How can they most suitably complement each other?

- Can private sector alternatives begin to improve the ability of the elderly to finance their own long-term care expenses without reform of Federal programs of support? Currently many elderly persons have no other choice but to incur sizable out-of-pocket expenditures for long-term care, depleting their incomes and assets to become eligible for Medicaid's nursing home benefit. For these persons, Medicaid offers protection of the last resort. Others have pointed out that Medicaid is used by far more than a low-income population and that many middle income individuals are transferring their assets to relatives in order to qualify for Medicaid's nursing home benefit before actually incurring catastrophic long-term care expenditures. The Health Insurance Association of America has suggested reducing Medicaid's involvement in the financing of nursing home care so that fewer middle income individuals can use the program as a viable option for their long-term care needs. However, little is known about the number of persons who actually transfer assets in order to qualify for Medicaid's nursing home benefit. Out-of-pocket expenditures for nursing home care, on the other hand, amount to half of total national expenditures and are this high because private sector coverage is very limited and elderly persons must deplete their incomes and assets. Given these considerations, how should reform of public programs proceed?

- Public programs and limited private insurance currently provide more support for institutional forms of long-term care than for community-based care. Uncertainty about the costs of expanded community-based care has inhibited the broadening of coverage for these services. There appears to be consensus, however, that regardless of the cost of community-based services as compared to institutional care, community care is the more desirable option for most persons with chronic disabilities. Despite the prevalence of chronic conditions, most older persons are in reasonably good health and most chronically ill persons want to be as self-sufficient and independent as possible. There is also substantial evidence that family members would prefer to continue providing support services if some form of assistance were available to make their continued efforts possible. What kinds of controls must be in place for home care coverage to be more extensively included in public or private financing programs for long-term care? Can expanded home care coverage be included only in a managed care setting such as a social/health maintenance organization or life care community?

o What are other viable options for enhancing the elderly's ability to finance long-term care expenses without impoverishment? Some have encouraged Federal and State tax modifications, ranging from incentives to encourage families to continue to provide long-term care to tax-preferred cash accumulation plans, such as IRAs for long-term care. Others have pointed to the need to expand incentives for congregate housing arrangements such as life care communities.

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Senator MITCHELL. Good morning, ladies and gentlemen. Good morning, Senator Mikulski. We begin today's series of hearings on long-term care. The American health care system is unequalled in its ability to provide high quality and comprehensive acute health care.

While our attention has been focused on remarkable achievements like organ transplantation and shock trauma units, we have failed to recognize the growing needs for the care of chronic illnesses. Whether one measures the need in terms of demographic data or in the more important terms of human suffering, the need for long-term care is great.

Recent interest in catastrophic health care insurance has also been focused on acute care rather than chronic care; yet only ten percent of the catastrophic expenses faced by our older citizens result from acute care. By contrast, long-term care expenses account for more than 80 percent of the problem.

While we must move forward to relieve the burden imposed by acute catastrophic expense, we cannot simply ignore the problem of long-term care. The services required by individuals and their families in coping with chronic illnesses are much more diverse than those for acute care. Housing, nutrition, transportation, help with housework, and help with personal care are just a few of the services that are necessary adjuncts to medical, nursing, and psychosocial care. In some areas of the country older persons can find some or all of these services, but they often face a bewildering array of providers, eligibility requirements, and charges.

In other areas, there are simply no services available. In the face of this need, we have no effective system of either delivering or financing long-term care. The result is needless personal and financial hardship.

Unfortunately, the problems inherent in developing a system of high-quality, comprehensive, and affordable care are considerable. Even more difficult is finding an equitable and politically acceptable method of financing care for chronic illness. While the solutions to the current crisis in long-term care will be complex and difficult to achieve, we must begin to address the needs of elderly Americans in the availability and financing of such services.

Today, I plan to introduce two pieces of legislation which address specific problems in the delivery of long-term care to the elderly. One of these, the Medicaid Community Spouse Protection Act of 1987, is an attempt to resolve the problem of spousal impoverishment that results when one spouse remains at home in the community and the other spouse requires institutionalization. This inequity has caused women all over the country to be forced into poverty.

Spousal impoverishment is an issue which was originally brought to my attention by advocates for the elderly in Maine. It is also a matter of great concern to a number of national organizations such as the AARP and the Older Women's League.

I am pleased that Senator Mikulski will testify for this subcommittee today, addressing the issue of spousal impoverishment, an issue she has been committed to for some time. I look forward to working with Senator Mikulski and other interested Senators in developing a viable proposal which will remedy the current situation which forces too many elderly women into poverty.

As I said earlier, this is the first of three hearings planned to address the problems of long-term care. This hearing will provide us with an overview with a focus on service needs. Our second hearing will be concerned with the quality of care, and the last with financing.

I hope these hearings will mark the turning point where we begin to move beyond the description of the problem to a description of the solution. We can afford no less.

I am pleased that Senator Packwood is here today. Senator, do you have an opening statement?

Senator PACKWOOD. I have no opening statement, although I agree wholeheartedly with you.

Senator MITCHELL. I thank you. I wanted to announce that Senator Heinz had planned to be here today but will not be here due to a death in his family. He will submit questions for the three panels, though, for the record.

With that, Senator Mikulski, welcome. We look forward to hearing from you.

STATEMENT OF THE HONORABLE BARBARA A. MIKULSKI, UNITED STATES SENATOR FROM THE STATE OF MARYLAND

Senator MIKULSKI. Thank you very much, Mr. Chairman. I want to thank you for the opportunity for participating today, as you begin your examination of the serious problem of this country's long-term health care needs. I congratulate you on the introduction of your legislation and am happy to co-sponsor the legislation that you are advocating.

So much of the recent discussion has focused on how our country will finance catastrophic health care. What has been overlooked in the discussion is the tragic status of what I call "nursing home widows and widowers"—the spouses of long-term care patients. I want to compliment you, Mr. Chairman, for focusing on one of the most critical aspects of long-term care problems—spousal impoverishment. Neither the Administration or most members of Congress have focused on this.

I know only too well the emotional and financial burdens of families who need to provide long-term care to a family member. My own father has Alzheimer's Disease; and after the exhaustion of family care and support services through day care, we finally needed to turn to long-term care. We were able to grapple with that because of the resources within my own family; but not every family has a daughter who is a United States Senator who can help when this crisis occurs—either to deal with the red tape, understand the complications of spend-down, or provide a safety net.

As you know, Mr. Chairman, thousands of elderly citizens each year face a traumatic situation. They need to place their sick spouse in a nursing home. This often comes at a time of mental and physical exhaustion, coupled with a sense of guilt, by the spouse that he or she can no longer care for their disabled spouse. Adding to the emotional strain is the discovery that Medicare does not pay for long-term care. The couple soon realizes that the cost far exceeds the couple's available resources, even though they played by the rules and saved for their retirement.

Mr. Chairman, I can't tell you the number of calls that I get, particularly from the children of someone in a nursing home, who calls and says: Senator Mikulski, is it true that Medicare doesn't pay for long term care? I thought it paid for 100 days. The answer is: No, except under the most limited and adverse circumstances. They said: Well, my mom has had a stroke, and when she hears about what we have to do—sell her home and get rid of the family assets—she is going to have another one. And that is about where we are.

The couples, in order to qualify for Medicaid, must spend down to the determined Medicaid eligibility level in order to qualify for Medicaid assistance, the only public financing for long-term care. This problem is particularly acute for older women who are often left without sufficient income to meet even their most basic needs.

Let me give you an example about how this works by describing a typical couple and their finances. All of their lives they worked and said: This is our money. Until they face Medicaid eligibility, and suddenly it is separated out into his money and her money, and her money is very little.

In this case, the husband and wife own their own home worth $50,000 and a five-year-old car worth less than $4,500. Their joint savings account contains $35,000. The husband receives $550 a month in Social Security; the wife receives $250 a month in Social Security; and they receive $200 a month in annuity payments in his name. These are their assets when the husband becomes ill and must enter a nursing home.

At that point, they must spend down to become eligible for Medicaid assistance. Under most typical Medicaid State programs, the wife is able to keep the house and car, but knows that when other monies are exhausted, a lien will be placed on the house. From their joint savings account, she can keep half, or in this case, $17,000.

The remaining money is made available to pay for her husband's care. Out of their monthly income she keeps only her personal income of $250 a month, plus some other minimal benefits from that. That means that where the couple had $1,000 in monthly income, she must live on $292. That means impoverishment. That means bankruptcy. That means more stress on a family.

I am pleased to co-sponsor the Medicaid Community Spouse Protection Act, which you will soon address. It addresses this problem by guaranteeing a more adequate monthly income, which is a critical part of the solution to spousal impoverishment. I have in the past, as a Member of the House, and will again introduce legislation that deals with various problems relating to this issue.

I believe, Mr. Chairman, that it will be useful to examine a variety of options as we in the Congress address this national tragedy of ill-conceived rules and regulations that reward the ne'er-do-well, that reward the squanderer. If my father had spent his life savings by going to Atlantic City and gambling his money away, we would be eligible for the same Medicaid. If my father had taken a look and said I don't have the memory I did, so let's spend now because I want to know if I live later, and if he had taken my mother on an around-the-world cruise on Love Boat, my mother would have at least had some other memories.

They felt that by saving they could care for themselves. But we found by saving, we only had to turn it over to the Medicaid rulers and regulators. Circumstances of fate ruin the health of many Americans in their retirement, years they should enjoy, not dread. We in the Federal Government cannot stand by idly and watch while our present system pays for those who need long-term care and forces their spouses into poverty; but that is what we are doing, and that is what we must correct.

And I look forward to working with you on this most important national issue. Thank you.

Senator MITCHELL. Thank you, Senator. I commend you again for your interest in this issue. While I have not had an opportunity to review your legislation, I understand it does include a provision which addresses the assets issue. As you may know, the bill I am sponsoring does not address that issue, and I wonder if you could explain that provision in your legislation.

Senator MIKULSKI. Yes, Mr. Chairman. You see, the bill that I will be introducing later this month will deal with enabling people to not have to liquidate all of their assets.

Now, once half of their life savings are spent down, and the monthly income is inadequate to meet the bills, the State will place a lien on assets. This then means that it results in further impoverishment of families, and I think we have to take a look at assets, one of which of course is the bank account; the second of course is if the widow has a car, which in many instances is important to be able to move around for her own independence and viability; and then there is this other issue of what happens to the home. Very often, families resort to convoluted ways to come under Medicaid's radar to escape the rules. And I can tell you that for people who have saved and own their own home, the idea of losing that home or having a lien on it adds further to the stress that I call "the nursing home widow."

I would recommend that we really take a look at assets. And I am not talking about if they have their own home, two condos, $50,000 worth of silver; I am not talking about those kinds of assets. But I think a family should be able to keep what we would call a minimum family nestegg of assets.

Senator MITCHELL. Thank you very much, Senator.

Senator PACKWOOD. No questions, Mr. Chairman.

Senator MITCHELL. Thank you very much.

Senator MIKULSKI. And I thank you, Mr. Chairman, because wherever I go, the two issues that I hear facing American families now are the issues of day care in order that women can reenter the marketplace, and then this issue of Medicare and long-term care. This seems to be placing the most enormous stress on families coping with their new economy and new needs. Thank you very much.

Senator MITCHELL. Thank you. The next panel will include Marjory Blood, Jacob Clayman, Victoria Jaycox, and Stanley J. Brody. I would ask those persons to come forward, please.

Good morning, ladies and gentlemen, and welcome. I would like to begin by reminding you and all future witnesses of the procedures by which the committee operates.

First, your written statements will be placed in the record in their entirety. We have a long hearing today—12 witnesses—and so, I am going to ask each of you to summarize your statements in five minutes or less.

When four minutes have elapsed, this orange light will go on, and at five minutes, the red light will go on; and I am going to strictly enforce that today because, otherwise, it is very unfair to the witnesses who are later on the schedule, who if we don't adhere to that now, simply won't get a chance to testify.

So, I will ask you all to terminate your remarks when the five minutes is up, and then we will have time for questions; and we will be able to hear all of your important points.

We will begin with Ms. Blood, who is a member of the National Legislative Council of the American Association of Retired Persons, and has the good fortune to live in Maine. Welcome, Ms. Blood.

[The prepared written statement of Senator Mikulski follows:]

BARBARA A. MIKULSKI
MARYLAND

United States Senate
WASHINGTON, DC 20510-2003

TESTIMONY BEFORE SUBCOMMITTEE
ON HEALTH
COMMITTEE ON FINANCE

FEB. 24, 1987

MR. CHAIRMAN, THANK YOU FOR THE OPPORTUNITY TO PARTICIPATE TODAY AS YOU BEGIN YOUR EXAMINATION OF THE SERIOUS PROBLEM OF THIS COUNTRY'S LONG TERM HEALTH CARE NEEDS.

SO MUCH OF THE RECENT DISCUSSION HAS FOCUSED ON HOW OUR COUNTRY WILL FINANCE CATASTROPHIC HEALTH CARE. WHAT HAS BEEN OVERLOOKED IN THE DISCUSSION IS THE TRAGIC STATUS OF THE SPOUSE OF A LONG TERM CARE PATIENT.

I WANT TO COMPLIMENT YOU, MR. CHAIRMAN, FOR FOCUSING ON ONE OF THE MOST CRITICAL ASPECTS OF THE LONG TERM CARE PROBLEM -- SPOUSAL IMPOVERISHMENT. NEITHER THE ADMINISTRATION NOR MOST MEMBERS OF CONGRESS HAVE FOCUSED ON THIS.

I KNOW ONLY TOO WELL THE EMOTIONAL AND FINANCIAL BURDENS OF FAMILIES WHO NEED TO PROVIDE LONG TERM CARE TO A FAMILY

MEMBER. MY OWN DAD BECAME ILL AND NEEDED THIS CARE. NOT EVERY FAMILY HAS A DAUGHTER WHO IS A U.S. SENATOR WHO CAN HELP WHEN THIS CRISIS OCCURS, AND I KNOW HOW HARD IT HAS BEEN FOR US.

AS YOU KNOW, MR. CHAIRMAN, THOUSANDS OF ELDERLY CITIZENS EACH YEAR FACE A VERY TRAUMATIC SITUATION --- THE NEED TO PLACE THEIR SICK SPOUSE IN A NURSING HOME. THIS OFTEN COMES AT A TIME OF MENTAL AND PHYSICAL EXHAUSTION COUPLED WITH A SENSE OF GUILT BY THE COMMUNITY SPOUSE THAT HE OR SHE CAN NO LONGER CARE FOR THEIR SICK SPOUSE.

ADDING TO THE EMOTIONAL STRAIN IS THE DISCOVERY THAT MEDICARE DOES NOT PAY FOR LONG TERM CARE. THE COUPLE SOON REALIZES THAT THE COST FAR EXCEEDS THE COUPLE'S AVAILABLE RESOURCES, EVEN THOUGH THEY "PLAYED BY THE RULES" AND SAVED FOR THEIR RETIREMENT.

THE COUPLE MUST THEREFORE "SPEND DOWN" TO THE STATE-DETERMINED MEDICAID ELIGIBILITY LEVEL IN ORDER TO QUALIFY FOR MEDICAID ASSISTANCE. THIS PROBLEM IS PARTICULARLY ACUTE FOR OLDER WOMEN WHO ARE OFTEN LEFT WITHOUT SUFFICIENT INCOME TO MEET EVEN THEIR MOST BASIC NEEDS FOR SUBSISTENCE.

LET ME GIVE YOU AN EXAMPLE OF HOW THIS WORKS BY DESCRIBING A TYPICAL COUPLE AND THEIR FINANCES.

THE HUSBAND AND WIFE OWN THEIR HOUSE WORTH $50.000 AND A

FIVE-YEAR OLD CAR WORTH LESS THAN $4,500. THEIR JOINT SAVINGS ACCOUNT CONTAINS $35,000. THE HUSBAND RECEIVES $550 A MONTH FROM SOCIAL SECURITY AND THE WIFE RECEIVES $250. THEY ALSO RECEIVE $200 A MONTH FROM INSURANCE PAYMENTS.

THESE ARE THEIR ASSETS WHEN THE HUSBAND BECOMES ILL AND MUST ENTER A NURSING HOME.

AT THAT POINT, THEY MUST "SPEND DOWN" TO BECOME ELIGIBLE FOR MEDICAID ASSISTANCE. UNDER A TYPICAL STATE MEDICAID PROGRAM, THE WIFE IS ABLE TO KEEP THE HOUSE AND CAR. FROM THEIR JOINT SAVINGS ACCOUNT, SHE CAN KEEP ONLY $1700. THE REMAINING $33,000 IS MADE AVAILABLE TO PAY FOR HER HUSBAND'S CARE.

OUT OF THEIR MONTHLY INCOME, SHE KEEPS ONLY HER PERSONAL INCOME OF $250 A MONTH, PLUS $42 OF THE COUPLE'S TOTAL INCOME, WHICH ADDS UP TO THE MAXIMUM MONTHLY INCOME ALLOWED UNDER MARYLAND'S MEDICAID REGULATIONS OF $292. THUS, OF THE COUPLE'S $1000 MONTHLY INCOME, THE WIFE MUST LIVE ON ONLY $292.

I AM PLEASED TO COSPONSOR THE MEDICAID COMMUNITY SPOUSE PROTECTION ACT, WHICH YOU WILL SOON INTRODUCE. IT ADDRESSES THIS PROBLEM BY GUARANTEEING A MORE ADEQUATE MONTHLY INCOME, WHICH IS A CRITICAL PART OF THE SOLUTION TO SPOUSAL IMPOVERISHMENT.

I HAVE IN THE PAST, AND WILL AGAIN INTRODUCE LEGISLATION THAT

DEALS WITH THE VARIOUS PROBLEMS RELATING TO SPOUSAL IMPOVERISHMENT. I BELIEVE, MR. CHAIRMAN, THAT IT WILL BE USEFUL TO EXAMINE A VARIETY OF OPTIONS AS WE IN THE CONGRESS ADDRESS THIS NATIONAL TRAGEDY OF ILL-CONCEIVED RULES AND REGULATIONS.

CIRCUMSTANCES OF FATE STEAL THE HEALTH OF TOO MANY AMERICANS IN THEIR RETIREMENT YEARS -- YEARS THEY SHOULD ENJOY, NOT DREAD.

WE IN THE FEDERAL GOVERNMENT CANNOT STAND IDLY BY AND WATCH WHILE OUR PRESENT SYSTEM PAYS FOR THOSE WHO NEED LONG TERM CARE, AND FORCES THEIR SPOUSE INTO POVERTY. BUT THAT'S EXACTLY WHAT WE'RE DOING, AAND THAT'S WHAT WE MUST CORRECT.

MR. CHAIRMAN, I LOOK FORWARD TO JOINING WITH YOU TO DEVELOPE A CONCRETE AND ACHIEVABLE SOLUTION TO SPOUSAL IMPOVERISHMENT.

STATEMENT OF MARJORY BLOOD, MEMBER OF THE NATIONAL LEGISLATIVE COUNCIL, AMERICAN ASSOCIATION OF RETIRED PERSONS, AUGUSTA, ME

Ms. BLOOD. Thank you, Senator Mitchell. On behalf of the more than 24 million members of the American Association of Retired Persons, I want to thank you for this opportunity to state the Association's views on the need to reform our nation's long-term care policies and express our appreciation for the subcommittee's interest in addressing long-term care, an issue of increasingly vital concern to millions of American citizens.

According to a recent national survey of persons aged 21 and over conducted for the AARP, the cost of long-term health care and/or catastrophic illness is now seen as the single most worrisome burden that families—not just the elderly—must face in living up to their responsibilities.

More than three out of four Americans in all age groups said they favor expansion of the Medicare program to include the costs of long-term health care which otherwise would be borne by the family. We view these findings as indicative of the growing public support for change.

For today's hearing, we were asked to provide an overview of long-term care. After briefly defining long-term care and noting who needs it, I would like to focus on four key points: (1) families who are the bulwark of the long-term care delivery system need support; (2) we must expand in-home and other community-based services; (3) by far the most important catastrophic health care expense for older Americans is that of long-term nonskilled care; AARP and others are concerned that this point is not being adequately addressed in the current "catastrophic" debate; and (4) there is a need for universal long-term care insurance.

While there are no simple solutions to reforming the long-term care system, AARP believes that there are feasible, affordable steps we can take in that direction both this year and beyond.

In layman's terms, long-term care is the assistance needed to live as independently, decently, and meaningfully as possible when disabilities undermine physical or cognitive capacities. A full continuum of long-term care services should include in-home assistance and other community-based services, specialized housing, and high quality institutional care. Long-term care is potentially needed by persons of all ages, but older people represent the majority of those needing such assistance.

The most critical determinant of demand for long-term care is the dramatic growth of the population aged 85 and over. First, family members are the major providers of long-term care services. These caretakers—predominantly middle-aged and older women—are a highly vulnerable group.

Many are spouses who are themselves old, poor, and in ill health. Many are adult daughters caring for older parents, who are also working outside of the home and caring for their children. Yet services which would buttress caregivers such as respite care are very limited. The often expressed fear that families will significantly reduce the assistance they are now providing if home and community-based services are made more widely available has no basis in fact.

Given the stronger preference of older people to remain in their own homes, the lack of access to community-based services is the most pressing gap in the current long-term care system. AARP believes that it is necessary to expand community-based services, even though the overall cost could increase in the short term as a result of additional demands. There are powerful reasons for such expansion. Such services often result in better care. They fulfill unmet needs, and they are desired by American citizens.

By far the most critical need for catastrophic protection for older Americans is for help with the costs of long-term chronic illness. Few people can afford the expense of an extended nursing home stay which now averages nationally over $22,000 per year. Medicare and private insurance pay only a miniscule proportion of nursing home costs.

As a result, many older people eventually end up on Medicaid. To be eligible for Medicaid, couples often spend down their combined income and assets, leaving one spouse—usually the wife—destitute.

The Association believes there is a need to provide universal protection against catastrophic costs of long-term care, based on the insurance principle of shared risk. At any one time, a relatively small proportion of our population will face catastrophic long-term care expenses. One out of every four persons over the age of 65 will be admitted to a nursing home in the course of his or her lifetime.

These facts argue inherently for an insurance approach to the problem. Responsibility for long-term care insurance must be shared between the public and private sectors of our economy. However, even a predominant reliance on private sector approaches is not likely to be a viable solution to the long-term care financing problem, and additional Government funds will be needed.

The Association recognizes the need for comprehensive reform of the long-term care system, which experts have labeled a "shambles." AARP's National Legislative Council recently made this one of its top priorities. Political realities, however, suggest that the nation is not yet ready to undertake a major overhaul of long-term care policies or to find financing to provide true protection against the catastrophic costs of long-term care.

Several incremental steps, however, can feasibly be taken this year to provide urgently needed protection for American families. These include preventing the impoverishment of spouses by those who need nursing home care, improving the quality of institutional and home health care, establishing a national mandatory income standard for medical eligibility, and increasing support for caregivers such as respite care.

Senator MITCHELL. Thank you very much. The next witness is Jacob Clayman, who is President of the National Council of Senior Citizens of Silver Spring, Maryland. Mr. Clayman, welcome.

[The prepared written statement of Ms. Blood follows:]

AARP

STATEMENT

of the

AMERICAN ASSOCIATION OF RETIRED PERSONS

on

LONG-TERM CARE

before the

SENATE FINANCE COMMITTEE

Subcommittee on Health

Washington, D.C.
February 24, 1987

Presented by:

Marjory Blood
Member, AARP National Legislative Council

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John T. Denning *President* Cyril F. Brickfield *Executive Director*

Introduction

Thank you, Senator Mitchell. My name is Marjory Blood. I am a member of AARP's National Legislative Council and of the Maine Committee on Aging. I also chair the Advisory Committee for Maine's Long-Term Care Ombudsman Program. On behalf of the more than 24 million members of the American Association of Retired Persons, I want to thank you for this opportunity to state the Association's views on the need to reform our nation's long-term care policies.

Before I begin, however, I would like to express AARP's appreciation for the Subcommittee's interest in addressing long-term care. We are aware of the many difficult issues that this Committee must face in a period of constrained budget resources. We are pleased that you have chosen to address long-term care, an issue of increasingly vital concern to millions of American citizens.

According to a recent survey of persons aged 21 and over conducted for AARP by the Daniel Yankelovich Group, the cost of long-term care health care and/or catastrophic illness is now seen as the single most worrisome burden that families - not just the elderly - must face in living up to their responsibilities. More than 3 out of 4 Americans, in all age groups, said that they favor expansion of the Medicare program to include the costs of long-term health care which otherwise would be borne by the family. We view these findings as indicative of the growing public support for change.

For today's hearing, we were asked to provide an overview of long-term care. This is a broad and complex topic. After briefly defining long-term care and noting who needs long-term care services, I would like to focus on four key points: (1) Families are the bulwark of the long-term care delivery system and any proposals for reform must consider their needs; (2) There is an urgent need to expand community-based long-term care services; (3) By far the most important catastrophic health care expense to older Americans is the cost of long-term, non-skilled care. AARP and others are concerned that this point is not being adequately addressed in the current "catastrophic" debate; and (4) There is a need for universal long-term care insurance. Finally, AARP believes that, while there are no simple solutions to reforming the U.S. long-term care system, there are feasible, affordable steps we can take in that direction both this year and beyond.

What is Long-Term Care and Who Needs It?

In formal language, long-term care is a set of health, personal care, and social services delivered over a sustained period to persons who have lost or never acquired some degree of functional capacity, measured by an index of functional ability.

In laymen's terms, it is the assistance needed to live as independently, decently, and meaningfully as possible when disabilities undermine physical or cognitive capacities. Ultimately, long-term care concerns how very vulnerable persons live and die.

By its very nature, long-term care sits at the intersection between health and social services. While functionally impaired older persons need timely and appropriate health services, their most pressing need is often for "social care" services, ranging from occasional help with shopping and transportation to intensive personal care services. Medicare beneficiaries, including the chronically ill, may also require post-hospital or "transitional" care services, such as Medicare home health or skilled nursing facility care. AARP is increasingly concerned about problems in obtaining access to these services. However, since "transitional" care services are part of the acute health care sector, we are excluding them for the purposes of today's discussion. Of course, we would be more than happy to discuss these issues with the Subcommittee at the appropriate time.

The Association believes there should be a comprehensive, coordinated policy for and system of long-term care which is responsive to the changing dynamics of our population and family structures. Basic changes in the present system are necessary to assure a full continuum of long-term care services in the least restrictive setting possible. These long-term care services should include (1) in-home assistance, such as homemaker/chore services, personal care, home nursing care, and home-delivered meals; (2) community-based services, such as adult day care, transportation, respite care, telephone reassurance, and friendly visiting; (3) specialized housing, such as congregate housing with common services, and board and care homes; and (4) high quality institutional care.

Long-term care is potentially needed by persons of all ages, including young adults who are physically disabled, the developmentally disabled, and the chronically mentally ill. Older people, however, represent the majority of those requiring long-term care, and the need for assistance due to functional impairments increases steeply with age. For example, only 7% of persons aged 65-74 need help with one or more "instrumental" or "basic" activities of daily living, compared with almost 45% of those aged 85 or older.

The most critical determinant of demand for long-term care is the dramatic growth in the population aged 85 and over -- the fastest growing age group in the U.S. Based on current utilization patterns of institutional care, the population needing nursing home care is expected to almost double between 1985 and the year 2020. Moreover, the number of persons needing community-based long-term care will also grow rapidly. Data from the National Long-Term Care Survey conducted by the Department of Health and Human Services indicate that large numbers of functionally impaired older persons in the community, and particularly the severely disabled, have unmet needs for assistance. For example, 77% of older people with 3 or more limitations in their activities of daily living reported they needed more help.

Families as the Major Providers of Long-Term Care

Family members provide the great majority of the long-term care services received by functionally impaired older Americans, most of whom reside in the community (71%) rather than in institutions. More than 70% of these individuals rely exclusively on unpaid sources of care provided by informal caregivers.

Caregivers, who are predominantly middle-aged and older women, typically provide care seven days a week. Moreover, caregivers represent a highly vulnerable group. According to the 1982 National Long-Term Care Survey, one-third are over age 65, live in poverty or near poverty, and describe their health status as only "fair" to "poor." Almost one-half (44%) of adult daughters providing care to older parents are employed outside of the home, and one-quarter have children under the age of 18.

Although caregivers face many competing demands and are under considerable stress, services which could buttress them in their efforts, such as respite care and in-home assistance, are very limited. According to the National Long-Term Care Survey, less than 10% of caregivers to the frail elderly make use of any formal services. With few exceptions, these families are carrying the burden alone.

Fears are often expressed that families will abandon their caregiving responsibilities if home and community-based services are made more widely available. Yet there is no evidence, either in the U.S. or in nations with more fully developed community care systems, that families significantly reduce the amount of assistance they are providing when formal services are introduced. Much more could be done, however, to buttress them in their caregiving efforts.

Gaps in Community Based Long-Term Care Services

Given the strong preference of older peopole to remain in their own homes, the lack of access to community-based services is the most pressing gap in the current long-term care system. Compared to expenditures for institutional care, expenditures for community-based services are minute. Medicare's expenditures for home health services, which are limited to skilled nursing and rehabilitative care, represented only 2.4% of the Medicare budget in 1985. Expenditures for community-based services under Medicaid are similarly limited. Less than 2% of Federal-state Medicaid expenditures are for home health services. In addition, the numbers served under the Medicaid 2176 Waiver program, which allows states to provide a range of community services, have remained very small.

While home care, including homemaker and personal care services, is a service category under Title III of the Older Americans Act, the low level of resources allocated to the program severely restrict its impact. Similarly, the Social Services Block Grant program under Title XX, which primarily serves low income people, provides a variety of social services to a diverse population and faces many competing demands. Its support to the long-term care population is limited.

The time has come to acknowledge that expanding community-based long-term care services is necessary, even though overall costs could increase as a result of additional demand. There are powerful reasons for expanding such services: they often result in better care, they fulfill unmet needs, and they are desired by American citizens. Over the long term, expansion of community-based long-term care services will result in a more balanced, efficient system of providing long- term care.

The Catastrophic Costs of Long-Term Care

By far the most critical need for catastrophic protection for older Americans is for help with the costs of long-term, chronic illness. Nursing home stays account for over 80% of the expenses incurred by older people who experience very high out-of-pocket costs for health care (over $2,000 per year).

The need for long-term care leads almost inevitably to an unmanageable financial burden because the costs of care -- be it in an institution or in the home -- are often enormous. The annual cost of care in a nursing home, for example, now averages nationally over $22,000. Medicare and private insurance combined pay only a miniscule proportion of nursing home costs (less than 3% in 1985). More than half of nursing home costs are paid out of the pockets of residents or their families. Most of the remaining costs are paid under Medicaid, a means-tested welfare program. To qualify for Medicaid, one must either be poor or reduced to poverty in the process of trying to pay for care.

Few people can afford the expense of an extended nursing home stay, so many eventually end up on Medicaid, but only after financial catastrophe has occurred. Fully one-half of Medicaid dollars for nursing home care is spent on behalf of persons who enter nursing homes as private paying residents. The process of "spending-down" one's income and depleting one's assets to qualify for Medicaid can occur very quickly. A 1985 study conducted for the House Aging Committee found that approximately 2/3 of single older persons and 1/3 of couples in Massachusetts were impoverished after only 13 weeks in a nursing home.

As such statistics indicate, the impoverishment of a spouse in the community in order to finance the care of an institutionalized mate is one of the most serious problems facing older couples today. To be eligible for Medicaid, couples must often spend-down their combined income and assets, leaving one spouse - usually the wife - destitute. Many of the same women who are caught in the spend-down problem have spent years taking care of ill and disabled husbands at home.

Personal care services of indefinite duration in the home are not covered at all by Medicare, and the amount and type of home care provided under Medicaid is extremely limited in most states. Even those who can afford to pay for home health and other in-home services face often insurmountable barriers in locating competent, trained personnel. As a result of both limited access to home care and the very high expense of nursing home care, many older persons live in fear of becoming a burden on their families, or being forced to enter a nursing home and spend their lifetime savings in order to pay for care.

Some Priorities for Incremental Reforms in 1987

AARP recognizes the need for the comprehensive reform of the U.S. long-term care system, which experts have labeled "a shambles." Indeed, AARP's National Legislative Council recently made long-term care reform one of its top priorities. Political realities, however, suggest that the nation is not yet ready to undertake a major overhaul of long-term care policies, or to find financing to provide true protection against the catastrophic costs of long-term care.

Hence, the Association has selected several incremental steps which would provide urgently needed protection for American families with long-term care needs. We believe that these steps can feasibly be enacted by Congress this year:

o Prevent spousal impoverishment by reserving for spouses an asset level that allows them to live with dignity while still permitting the institutionalized spouse to qualify for Medicaid.

o Establish a nationa mandatory income standard for Medicaid eligibility. Currently, Medicaid eligibility ranges from under 20% of the poverty line in some states to over 90% in others.

o Make the services offered under the Medicaid 2176 program routine Medicaid benefits covered at the option of states. AARP strongly supports the Medicaid 2176 program, but opposes restrictive regulations implementing the program. The services authorized under the waiver -- case management, homemaker/home health aide and personal care services, adult day care, habilitation, and respite care -- are services basic to developing a meaningful system of home and community-based care.

o Increase supportive services, such as respite care and adult day care, for the caregivers to the frail elderly.

o Improve the quality of institutional care. The Association will be actively supporting legislation to improve the quality of life of the 1.5 million elderly and disabled Americans who reside in nursing homes. (We understand that this topic will be addressed in depth by this Subcommittee at a hearing later this year, and we hope to have the opportunity to present our views on this important issue at that time.) Nurses aide training, enforcement of federal standards, nurse staffing, and Medicaid discrimination, in particular, need to be addressed.

o Assure the quality of home care by improving the survey process, enforcing federal standards, developing training and certification requirements for personnel, and creating grievance mechanisms for consumers.

The Need for Universal Long-Term Care Insurance

Over the longer term, the Association believes there is a need to provide universal protection against the catastrophic costs of long-term care based on the insurance principle of shared risk. At any one point in time a relatively small proportion of our population will face catastrophic long-term care expenses. Although it is nearly impossible to predict just who those individuals will be, one out of every four individuals over the age of 65 will be admitted to a nursing home in the course of his or her lifetime. These facts argue inherently for an insurance approach to the problem. The costs to any one person will be small, while offering protection to all against catastrophic expenses.

Responsibility for long-term care insurance must be shared between the public and private sectors of our economy. AARP encourages the development of private sector approaches, as at least partial solutions, to the problem of financing the long-term care system the nation needs. Long-term care coverage, for example, should be offered as an optional benefit under group health plans.

We do not believe, however, that an exclusive or even a predominant reliance upon private sector approaches is likely to be a viable solution to the long-term care financing problem. Recent research by the Brookings Institution and ICF, Inc. indicates that private approaches would lead to only small reductions in total long-term care expenditures and the numbers of persons "spending down" onto Medicaid.

The Association believes that universal insurance coverage is needed to solve the problem of catastrophic long-term care expenses, and that additional funds will be needed to finance long-term care. Government expenditures will need to rise. If spread across peoples' working lives, comprehensive long-term care coverage is certainly affordable. Moreover, to a very real extent, these funds for insurance will come from shifting the burden away from the few who must now bear the brunt of the load to a broader population.

Conclusion

Today, American citizens have no protection against the risk of catastrophic long-term care expenses, a risk that can literally devastate middle income families. It is impossible for those who are aware of this situation - and growing numbers are - to feel secure about their own future or that of their loved ones. The fragmented U.S. long-term care "system" is seriously inadequate today and, barring major changes, will be increasingly inadequate in the future.

Finding ways to finance and deliver high quality long-term care services for functionally impaired persons will be one of the most pressing challenges confronting all levels of government in the coming decade. Such reform cannot be accomplished without the commitment of new public resources, a difficult task at a time of fiscal restraint. We must, however, move away from the current piecemeal, "welfare" approach to long-term care, which deprives American citizens of dignity and fundamental security. Because this concerns everyone in our society, AARP believes it is primarily a social insurance problem, where the appropriate pool is all Americans who need to be assured that they will have access to affordable and appropriate long-term care services.

The Association recognizes that there will be no simple solutions to the problem of reforming the U.S. long-term care system. Nevertheless, we have made this issue one of our highest priorities. We are pleased to offer our resources and assistance in the challenging task of developing meaningful responses to this pressing social need.

STATEMENT OF JACOB CLAYMAN, PRESIDENT, NATIONAL COUNCIL OF SENIOR CITIZENS, SILVER SPRING, MD

Mr. CLAYMAN. Thank you, Mr. Chairman and Senator Packwood. I don't know how many melancholy reports I have heard from elderly people, recounting their heartbreaking stories of long-term illnesses and the inevitable impoverishment that generally follows them thereafter.

I don't think I am being melodramatic when I say that that shouldn't happen in a humane, a caring, or a civilized society. That is why I appear here on behalf of the National Council of Senior Citizens, to plead the case of those elderly who ultimately will be struck by a long-term illness. It could be Alzheimer's or a stroke or various other ailments to which all old folks are prone. The need for action now is quite clear, indeed obvious.

The oldest of the old, 85 year of age and over, is the fastest growing population group in America. This group will increase by 20 percent this decade, compared to 10 percent of the growth of the general population.

This fact is exceedingly significant because the 85 and over require the most attention. Twenty-three percent of all 85 or over are now in nursing homes—amazing. Six percent in the 74 to 85 age groups are now in nursing homes. We all know that senior citizens spend enormous mountains of money for health care; $37.3 billion out-of pocket money, cash, in 1986, with $16 billion of it going to nursing homes. Medicare and Medigap policies don't do much. Medicare expenditures on skilled nursing facilities amount to only two percent—two percent—of the total national nursing home expenditures and one percent of the total Medicare budget.

Private insurance takes care only of one percent of the nation's nursing home bill. The grim reality is that too many elderly are forced to face the tremendous costs of nursing home care which is available to them only—only until they have spent themselves into poverty.

And what a sad conclusion to a long and productive life in our society. Today, we have a few modest suggestions to make; and indeed, they are modest, and sometimes I would be inclined to blush on other days to make these modest suggestions. And we do it because we appreciate the political temper of the time and the budget and the whole business.

First, Supplemental security income—SSI—those that are in that category, on entering the nursing home, the SSI payments cease, but the nursing home costs are paid by Medicaid and so, in essence, they are even there. They, however, get a $25.00 monthly stipend from SSI called "personal needs allowances" to take care of miscellaneous expenses, laundry, telephone calls, toothpaste, maybe even, if you have a sweet tooth, an occasional candy bar or something like that.

And those SSI elderly number 211,000. Another 600,000 nursing home occupants have personal incomes over SSI level, but incomes low enough to qualify for Medicaid. In these cases, the residents keep $25.00 personal needs allowance from their own personal income. Mind you, they are permitted to keep $25.00 for these miscellaneous expenses; and how generous of our society that we permit them this luxury.

We recommend that the PNA, the Personal Needs Allowance, be increased by $10.00, from $25.00 to $35.00. We urge that the COLA be attached to the PNA. The $25.00 allowance went into effect in 1972; no COLA was applied. If a COLA had been applied as it had been extensively throughout the system, then it would mean $60.00 now; we are only asking for $35.00 and the COLA be attached henceforth.

Secondly, husband and wife must both become impoverished before Medicare can be invoked, and this monstrosity—this monstrous, truly inhuman apparatus—needs mending. We recommend the uniform——

Senator Mitchell. If you can summarize, Mr. Clayman.

Mr. Clayman. I hardly can sneeze in five minutes and I find myself chained; but I want you to know, without going further, that I am simply in essence repeating the basis for the paper—the printed testimony—we have submitted. And I trust that our case will be made more extensively and more clearly there. So, I heed the chairman's admonition. I see the red light; it glares at me angrily. And I thank you.

Senator Mitchell. Your written statement may be more extensive, but it won't be more persuasive, Mr. Clayman. Thank you.

The next witness is Victoria Jaycox, Executive Director of the Older Women's League of Washington, D.C. Welcome, Ms. Jaycox.

[The prepared written statement of Mr. Clayman follows:]

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Long-Term Care and the Elderly

Testimony Presented Before the
Health Subcommittee
of the Senate Finance Committee

By

Jacob Clayman, President
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February 24, 1987
Washington, D.C.

First Vice President, Dr. Mary C. Mulvey, Providence, Rhode Island **Second Vice President,** George J. Kourpias, Washington, DC
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Mr. Chairman, my name is Jacob Clayman. I am President of the National Council of Senior Citizens, an organization with 4.5 million members.

The National Council of Senior Citizens welcomes this opportunity to address the important issues facing us in long-term care. Throughout our organization's history, we have devoted special attention to the health care needs of the elderly, especially the frailest and most vulnerable.

When a chronic illness strikes, most older Americans find that the long-term care services they need are not covered by Medicare, other public programs, or private Medigap insurance. As a consequence, many elderly persons and their families pay the full cost of their care out-of-pocket. The cost of long-term care has become the single greatest threat to the financial security of older Americans.

The inexorable growth of the elderly population--combined with other demographic and health care trends--is beginning to strain the resources available for long-term health care for the elderly. The number of people aged 65 and older doubled between 1950 and 1980, and will most likely double again by the year 2030, thereby entitling more than 20 percent of the population to be called "senior citizens." The number of the oldest old, those 85 and older, will increase by 20 percent this decade, compared to an expected ten percent growth for the general population. Even more striking, this oldest group is expected to increase three to four times faster than the general population in the next 20 years. In fact, by the year 2010, nearly 20 percent of our population will be in this age group.

This trend is especially important since rates of nursing home institutionalization increase dramatically with age. Only two percent of the elderly 65 to 74 years of age are in nursing homes, compared to six percent of the elderly 75 to 84 and 23 percent of those 85 and older. Given all these indications, the nursing home population is expected to increase by 57 percent from 1980 to 1995 and by three and one-half times by the year 2040, bringing the number of people living in nursing homes from 1.6 million today to 4.3 million.

The other side of the picture of the increased need for long-term care, of course, is the cost that this increased need will bring. The nation's nursing home bill for those age 65 and older will increase from $20.6 billion in 1980 to an estimated $52 billion in 1990. Altogether, the elderly, in 1986, spent out of their own pockets $37.3 billion on health care, $16 billion of which was spent on nursing homes alone. In this way, 1.6 million of the nation's elderly spent $16 billion, fully one-half of the nation's total nursing home bill, out of their own pockets. The average elderly household, in 1986, spent $2,670 in out-of-pocket costs, or 11.6 percent of gross income. Those over age 85 spent 42 percent of their income on out-of-pocket costs.

This is an enormous burden that the elderly and their families are forced to shoulder themselves. While most of the elderly think the Medicare program or their Medigap policies will help with these costs, this couldn't be much farther from the truth. Medicare expenditures for care in skilled nursing facilities equal only two percent of total national nursing home expenditures, and only one percent of the total Medicare budget. Similarly, private insurance covers only one percent of the nation's nursing home bill. The grim reality that many elderly are forced to face is that protection from these tremendous costs does not exist until they have spent themselves into impoverishment.

In our opinion, our continued reliance on a public policy that withholds health care protection until and unless hard-working citizens pauperize themselves is not something in which we can take pride. Clearly, faced with the problem in both financial and human costs, we need to find a more rational, well-coordinated approach to financing and providing long-term care than presently exists in this country. As a nation, we have found a way to provide health care coverage to seniors who need hospital and physician care. But our recognition of the need for health care coverage comes to a dead end at exactly the time when protection is most needed.

The need for long-term care cannot be overlooked for much longer. The growing number of seniors and their adult children demand a solution to this problem. The National Council of Senior Citizens understands the realities of Gramm-Rudman-Hollings and the chilling effect the Federal deficit has on good public policy generally and good health care policy specifically, and so we realize the full reform of the long-term care system may not occur as soon as we would like. Even with today's budget framework, however, we feel that concrete, important steps can be taken to improve the long-term care system in this country and the effect of our long-term care policies on our citizens. These steps will help make nursing home stays more bearable by increasing the living allowance given to nursing home residents; help prevent the impoverishment of one spouse because the other spouse needs nursing home care; and help enable seniors to get the Medicare home health care they need.

Nearly 800,000 Medicare nursing home residents depend on their "Personal Needs Allowance" each month--only $25.00 a month, or 82 cents a day--to cover a wide range of living expenses not paid for by Medicaid.

Nursing home residents in two categories receive Personal Needs Allowances (PNAs). Supplemental Security Income (SSI) recipients, once they enter a nursing home, no longer depend on SSI for their basic support because Medicaid covers their nursing home care, including room and board. However, they receive an SSI allowance of $25 a month to purchase personal need items not furnished by the nursing homes. About 211,000 nursing home residents receive PNAs through the SSI program. About 600,000 other nursing home residents have personal incomes over the SSI level, but their income is low enough to qualify them for Medicaid. In these cases, the residents are allowed to keep $25 a month of their person income for a PNA. The rest of their income is contributed toward the cost of their nursing home care.

The PNA is used to purchase basic supplies like toothpaste and shampoo, eyeglasses, clothing, laundry, newspapers and phone calls. In 15 states, more than half of the $25 must be spent on laundry alone. In addition to personal needs, many nursing home residents have substantial medical needs that are not covered by state Medicaid programs. Although the Personal Needs Allowance is not intended to cover medical items, these residents may have to save their PNAs over many months to pay for these costs, preventing them from tending to personal needs. In addition, if a nursing home resident enters a hospital, he must pay a daily fee to the nursing facility to reserve his bed there. Even though a resident who cannot pay the bed reservation fee is likely to lose his place in the facility, 40 percent of state Medicaid plans provide no coverage for bed reservations.

The $25 PNA has not been increased--even to adjust for inflation--since Congress first authorized payment in 1972. As a result, the PNA is worth less than $10 today. This means that all recipients of Social Security or SSI benefits have received COLAs to their benefits since 1974, except the frailest and most vulnerable--Medicaid nursing home residents.

The National Council of Senior Citizens advocates that Congress increase the PNA by $10 per month, plus a COLA, in order to restore just some of the purchasing power that nursing home residents have lost over the years. In fact, had the PNA been indexed by a COLA, Medicaid nursing home residents would receive $60 per month today. This small change from a $25 to a $35 PNA would help restore to Medicaid nursing home residents independence, dignity and just a small part of the purchasing power that Congress intended them to have. It would be small change for the Medicaid program, Mr. Chairman, and a big difference to recipients.

The second step we must take this year is to ensure that one spouse is not forced into poverty solely to enable the other spouse to receive needed nursing home care. The institutionalization of a spouse is often a very traumatic and dreaded step that is only taken when no other alternatives are available. Forcing a wife or husband to also impoverish her or himself so that the disabled spouse may receive long-term care is surely requiring too great a sacrifice of elderly couples who have been partners for life. But this is exactly the choice many elderly couples are forced to make because, unfortunately, the way in which Medicaid determines who is poor enough to qualify for assistance often results in two individuals becoming destitute before one is given any assistance.

In most states, older persons are eligible for Medicaid only if they meet the income standard of the Supplemental Security Income (SSI) Program. These benefits provide just 75 percent of the poverty line for individuals or $340 a month in 1987. Couples' benefits are just $510 a month. An individual is allowed to retain just $1,800 in assets; $2,700 for a couple. Some states use even more restrictive eligibility requirements for Medicaid.

At an average annual cost of $22,000, the expense of nursing home care quickly exhausts the resources of most persons. Only then does Medicaid assistance become available.

When an institutionalized person with a living spouse becomes Medicaid eligible, the law assumes that all marital income is available to cover the cost of nursing home care. After one month, the spouse at home, often the wife, may retain her own income and resources, if she has any left. Unfortunately, the wife is often dependent upon a portion of her husband's income, in which case Medicaid provides for a "spousal maintenance allowance." Federal law puts a ceiling on this allowance comparable to the SSI income standard or the state's "medically needy" standard. This usually results in about $350 to $400 a month being allocated to the spouse at home and, in some cases, the allowance is even less.

In short, there are two problems that cause spouses to face impoverishment. First, the practice of deeming one spouse's income and resources available to the other for the first month of institutionalization acts as a huge deductible from people who are already in desperate financial need. Second, the Federal law which sets spousal maintenance allowances below the poverty line is inadequate.

NCSC, as a part of a coalition of senior advocacy groups concerned with this issue, urges Congress to solve these problems and the terrible choices they force seniors to make as follows: First, end deeming of resources and income when one spouse is admitted to an institution; second, set a uniform Federal minimum spousal maintenance allowance equal to 150 percent of the Federal poverty line for couples, plus an adjustment for shelter costs and marital income; and, third, exclude liquid assets owned by the institutionalized spouse or by both spouses jointly up to $12 thousand in fair-market value for purposes of determining Medicaid eligibility.

Only through taking these humane and sensible steps can we ensure that institutionalization of an older American will not mean pauperization and loss of dignity, home and a life's worth of hard work for the spouse who is "lucky" enough to remain at home.

A third major problem in long-term care that the Congress needs to address this year is the unlawful and miserly limits that the Health Care Financing Administration (HCFA) has placed on the Medicare home health benefit. Four requirements must be met in order for Medicare beneficiaries to be eligible for Medicare home health benefits. One of the requirements is that the patient must require intermittent or part-time care. That is, if the patient needs full-time home health care, he or she is not eligible for the benefit. Since 1981, HCFA has used its own interpretation of the intermittent requirement to inappropriately restrict use of the Medicare home health benefit.

This problem has manifested itself in many ways. In 1980, Congress removed the limit on the number of visits allowed under the Medicare home health benefit. This action represented a major statement by the Congress that it was fully in favor of providing home health care to those in need and that it supported use of home care services as a substitute for costly institutional care. In 1981, however, HCFA issued instructions that had the effect of limiting the length of the home health benefit to no more than two or three weeks of part-time home health care. HCFA has also interpreted part-time to mean that even visits of only one or two hours each day constitute full-time care. As a result, many beneficiaries who need home health care beyond the two or three week "limit" are denied Medicare coverage.

These definitional squabbles might be no more than a thorn in the side of many seniors seeking the care they need if the problem hadn't been greatly exacerbated by implementation of the Medicare prospective payment system. When Congress, in 1983, moved to require the PPS system for Medicare hospital services, it did so with the deliberate reasoning that PPS would encourage greater use of less costly, more appropriate care in post-hospital settings--specifically at home and in skilled nursing facilities. And the health care system has responded exactly as Congress had intended and in accordance with the financial incentives put in place under PPS. Since 1983, hospital discharges to home health care are up 37 percent, senior citizens are leaving hospitals sooner and in greater need of care than ever before, and the provider community has responded to these needs by attempting to provide care and higher levels of care to more individuals at home.

This natural, correct, intended result of Congress' 1983 actions has not met with HCFA's approval, however. By all indications, it would appear that HCFA is trying to restrict use of the home health benefit to pre-1983 levels, even though the intent of Congress was to deliberately encourage greater use of this type of care. And creative use of the intermittent definition seems to be one of the most effective tools HFCA has in achieving this goal.

As a result of their creative energies, home health services are less available at a time when they are more needed than ever before, and Medicare patients are being forced to go without care they need, or pay out of their own pockets for care that they are entitled to under the law.

We believe that Congress should reassert its authority and its original intent that the home health benefit under Medicare should be available to senior citizens and that it should be used to provide needed transition care by explicitly stating in statutory language that the Medicare home health benefit should be available on a part-time basis to seniors in need of this care for up to 60 days, thereafter as certified by a physician that the care is still medically reasonable and necessary and that all other home health requirements are met.

If Congress were to act this year to provide a modest increase in the personal needs allowance available to Medicaid nursing home residents, ensure against pauperization of spouses of institutionalized older Americans, and ensure that the Medicare home health benefit provides the protection seniors really need, it will have taken concrete, meaningful, and compassionate steps to solve some of the most insidious problems facing the elderly who need long-term care.

A separate serious problem facing the elderly that we all have a grave responsibility to address is the issue of breaking the news to the elderly of America that the public programs they've relied on, and that they may rely on in the future, do not cover long-term care. I am very concerned, Mr. Chairman, that the public at large, but seniors especially, are being given a very false sense of security in thinking that the Administration's catastrophic illness plan will provide protection for the costs of long-term care.

Already, a large portion of the Medicare population believes the Medicare program provides long-term coverage--a belief they've been allowed to keep for far too long. Now, just as they're beginning to hear that this may not be the case, the Administration is holding out a new plan that, in the words of the President, will "give Americans that last full measure of security."

The greatest financial fear of many older Americans is the spectre of nursing home care and the last full measure of security they can be given is protection from the costs of long-term care. The President's comments, I greatly fear, will only cause seniors to shift from one false hope of relying on the Medicare program to answer these needs to another of relying on the catastrophic plan that the Administration has proposed.

I think its very important that we go forward with a catastrophic plan that builds on what the President has proposed, but I feel very strongly that it is incumbent upon all of us involved in shaping this public policy that we are very clear in describing just what the plan will--and won't--do for prospective beneficiaries. It would, in our opinion, be absolutely unconscionable if we were misleading on this information. If the plan would not include long-term care benefits, that message needs to get across. NCSC will do its part in trying to ensure that Medicare beneficiaries and their families have factual, full information on which to base their decisions on planning for future needs. Medicare beneficiaries must not be lulled into a pleasant, but erroneous belief that their long-term care needs will be met by paying $4.92 a month more in Medicare premiums.

The need for a solid responsible and comprehensive plan for long-term care financing is already upon us. Clearly, we must come to grips with this issue before the cost of taking even the most incremental steps are prohibitive. While we work toward a solution to the problem of long-term care financing, however, there remains plenty to be done to help ensure that this nation's elderly can live productive, dignified lives. I've tried to present the Committee with suggestions for just a few of these steps in my testimony.

Thank you again for the opportunity to testify this morning and I hope the Committee will continue to call on us for help in reaching our mutual goals.

STATEMENT OF VICTORIA JAYCOX, EXECUTIVE DIRECTOR, OLDER WOMEN'S LEAGUE, WASHINGTON, DC, ACCOMPANIED BY ALICE QUINLAN, DIRECTOR OF PUBLIC POLICY

Ms. JAYCOX. Thank you very much, Senator Mitchell, Senator Packwood, and Senator Chafee. I am Victoria Jaycox, Executive Director of the Older Women's League, the first national membership organization which focuses exclusively on midlife and older women. Accompanying me today is Alice Quinlan, our Director of Public Policy.

We appreciate very much the opportunity to give you our views on long-term care. Long-term care is a very important issue for the Older Women's League because long-term care is in fact very much a women's issue. It is a women's issue because women make up the majority of the elderly and of the frail elderly. It is a women's issue because older women are much more likely than older men to be unmarried and live alone and be in need of long-term care.

Long-term care is a women's issue because women are the primary caregivers of the elderly and because the burdens for them are so heavy that, without support, the result can be two frail and dependent adults instead of one.

And long-term care is especially a women's issue because women have lower incomes than men; and while they are more likely to need long-term care, they are also less likely to be able to pay for it. Paying for such care outright is very unlikely when the median income for an older woman is just over $6,000 a year. We are also concerned that, if financing of long-term care becomes totally privatized through long-term care insurance, older women may not fare well at all. Insurance companies are exercising great caution in marketing policies because of the high potential claims and their lack of actuarial experience.

And those most at risk of institutionalization, who are older women alone, may not be insurable or may not be able to afford the premiums.

We have a few recommendations for Congressional action today that deal with some problems that can and must be addressed over the short term. These issues need attention now because of their compelling nature and because of the expectations which are raised by the current attention in the media and in Congress directed to catastrophic health care costs and coverage.

In fact, it is too bad that you couldn't begin with a truth in advertising law on this subject because proposals right now that claim to be for catastrophic coverage but which do not include long-term care are misnamed, whether that is intentional or not. So, I will briefly discuss three concerns which we urge the subcommittee to address in the coming year: on health care restrictions, caregiver supports, and spousal impoverishment under Medicaid.

First, on health care restrictions. Current health care financing systems provide few realistic alternatives to institutionalization in either a hospital or a nursing home.

Medicare's prospective payment system has resulted in earlier discharges and only limited home health care service in the community. HCFA's interpretation in the regulations for Medicare is increasingly bizarre and increasingly restrictive and must, at a minimum, be restored to what Congress originally intended these regulations to be. That is the first recommendation.

In terms of caregiver support, among current proposals, we support legislation that would provide unpaid leave and job protection to workers caring for a seriously ill parent. That is very important for employed caregivers so they can maintain their jobs. However, what most caregivers say that they need is not so much financial assistance, but rather the provision of actual services and periodic relief from their caregiver burden. In this context, the notion that a tax break of several hundred dollars a year is a compelling incentive for someone to take on round-the-clock family care is a rather ridiculous one, from our point of view.

There does remain a very important role for Government in this area, though; and that is that both Medicare and Medicaid must provide greater funding for alternatives to hospital and nursing home services, including expanding coverage for skilled home health care, chronic nursing care, palliative care, respite care, hospice services, and adult day care. We think these are essential.

Our third concern is spousal impoverishment under Medicaid. As was noted earlier, spousal impoverishment results from the need to spend down assets in order to qualify for nursing home coverage under the Medicaid program. Right now, 10 to 12 percent of nursing home residents have spouses living in the community, which means that up to 75,000 spouses of recent nursing home patients have lost their assets due to Medicaid eligibility tests.

This becomes a real problem, not only for the present, but for the future. To remedy this tragedy of spousal impoverishment under Medicaid, the Older Women's League proposals two principles. First, the spouse must retain an amount of monthly income sufficient to meet that person's fixed expenses. We advocate an amount equal to the median income of elderly American couples, which is about $1,000 a month. Second, community spouses must be allowed to retain assets sufficient to support themselves with dignity throughout the rest of their lives, which is a period for some women of 15 to 20 years.

Savings equivalent to the median income of couples for a year or two would provide some of the security of these assets that the elderly seek in catastrophic coverage.

Senator MITCHELL. Thank you, Ms. Jaycox. Before proceeding to the next witness, I wanted to mention that we have been joined by Senator Chafee and Senator Bradley. Senator Chafee, do you have an opening statement?

Senator CHAFEE. Thank you very much, Mr. Chairman. I will put it in the record, but first I want to thank you for having these hearings. They are so important. And I also want to thank all the witnesses.

Unfortunately, I am a member of the Highway Conference and so, I will have to leave here at 11:00 a.m. I will read the testimony that has been submitted, and I think it is excellent. I was just looking at what Ms. Jaycox had to say about stressing the problems of women. And if you will look on page 3 of her testimony, there is a chart there that is extremely interesting, showing that 77 percent of men over 65 are married but only 38 percent of the women.

The difficulties of everybody in this category are large, but I think the women have a particularly serious problem. I want to thank you, Mr. Chairman.

I appreciate also the bill which you are introducing dealing with the spousal impoverishment, and I am delighted to be a co-sponsor of that.

Senator MITCHELL. Thank you, Senator Chafee. Senator Bradley, do you have a statement?

Senator BRADLEY. Mr. Chairman, I would only applaud you for holding this set of hearings. I think it is enormously important. There is a lot of disagreement on the long-term care issue, and we are probably some ways off to getting any kind of comprehensive solution; but I think there are some questions which we want to make sure we explore, such as the relationship between the public programs and the private sector financing of long-term care.

We will also want to look at the problem that public programs currently provide more help for institutional care than for community based care. So, Mr. Chairman, I would hope that we keep in mind that we are dealing with a population in an institutional setting, that is already over one million people in the country. And probably double that in a community-based setting. We need to bring together the private and the public sectors to try to deal with this problem because it is a very real problem.

I must say that in my State of New Jersey, I have gotten in the habit of delivering meals-on-wheels occasionally; and many times, when I walk into the home or the apartment of a senior citizen with a hot meal, I find them in a very precarious health circumstance. I think we just have to find a way to deal with their long-term health needs. So, I applaud you for the hearing and look forward to the testimony of all the witnesses.

Senator MITCHELL. Thank you, Senator Bradley. The next witness is Stanley J. Brody, who is Director of the Research and Training Center for Rehabilitation of Elderly Disabled Individuals at the University of Pennsylvania. Welcome, Mr. Brody.

[The prepared written statement of Ms. Jaycox follows:]

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STATEMENT ON LONG-TERM CARE

presented to the

HEALTH SUBCOMMITTEE

of the

SENATE FINANCE COMMITTEE

February 24, 1987

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Executive Director

Senator Mitchell, members of the subcommittee. I am Victoria Jaycox, Executive Director of the Older Women's League, the first national membership organization focused exclusively on midlife and older women. Founded in 1980, the Older Women's League now has 22,000 members and donors, and chartered chapters in 35 states. Through education, research and advocacy, our members work for changes in public policy to eliminate the inequities women face as they age.

Key items on OWL's national agenda are access to health care and related long-term care issues, including support for caregivers and alternatives to institutionalization.

We are grateful to you, Mr. Chairman, for calling these hearings to explore long-term care issues, and for giving us the opportunity to share our perspective on long-term care with you and with members of the subcommittee.

As I will use the term, "long-term care" is not limited to institutionalization, but means the entire continuum of care needed over a significant period of time because of chronic disease or disability.

Such care includes in-home services, adult day care, care in resident facilities such as board and care homes, convalescent homes, intermediate care and skilled nursing facilities. Ideally such an array of options enables an older person to remain independent and to live in the community as long as possible.

LONG-TERM CARE AS A WOMEN'S ISSUE

Long-term care is preeminently a women's issue. Women in the United States experience aging differently than men do, and those differences--in longevity, marital status, and income--highlight why long-term care is so critical an issue for women. They are also central to the development of realistic and comprehensive long-term care solutions. Compared with older men, women live longer, tend to live alone, and are much poorer.

o **Long-term care is a women's issue because women make up both the majority of the elderly and the majority of the frail elderly, whether in institutional or community settings.**

As of March, 1986, there were 27.3 million Americans age 65 and over, about 11.3 million men and 16.1 million women. Women thus comprise about 59% of all Americans age 65+. Because of differences in longevity, women outnumber men two to one in the older age categories, and this ratio increases with age. Table 1 gives an age-sex distribution of persons age 75 and over.

TABLE 1 -- Numbers of persons age 75+ in 1985, by sex and age (thousands)

Age	Men	Women	Total
75-79	2,120	3,361	5,481
80-84	1,182	2,285	3,467
85+	787	2,053	2,840
Total	4,089	7,699	11,788

(Source: Census Bureau, P-25, No. 985, Table A-1)

Since functional disability increases with age, women also constitute the majority of the frail elderly. "Frail elderly" are often defined as persons over age 75 who require assistance with daily living tasks. Given their predominance among the "old-old" age category, it is not surprising that over 70% of persons who reside in nursing homes are women.

o **Long-term care is a women's issue because older women are much more likely to be unmarried and living alone than are older men.**

When the marital status of older men and women is compared, there are no significant gender differences among those who are divorced, separated or never married. But there are profound differences in the proportions of men and women who are widowed or married. As Table 2 shows, most older men are married, while most older women are not. This is due to women's greater longevity, to the typical age differential in marriages (older man/younger woman), and to gender differences in remarriage rates.

Table 2 -- Marital status of persons age 65+ in 1985, by sex

Status	Men	Women
married	77%	38%
widowed	14%	51%
separated/divorced	6%	5%
never married	5%	6%

(Source: Census Bureau, P-20, No. 410, Table 1)

Because there are more older women than men, the result in absolute numbers is that many more older women are unmarried and live alone. In 1986, about 8.2 million older persons lived alone, and 80% were women; 6.2 million persons over age 75 were unmarried, and 82% were women.

The relationship between marital status/living arrangements and potential need for long-term care is obvious. Persons unable to turn to family members for caregiving at home require services for pay in a community or nursing home setting. Among nursing home residents, unmarried persons outnumber those who are married by eight to one.

- **Long-term care is a women's issue because women are the primary caregivers of the elderly.**

One implication of the marital status data given above is that most older men have a spouse to provide needed care; most older women do not. The primary caregivers in family settings are overwhelmingly wives and daughters, and then sisters, daughters-in-law, nieces and other women. Concern for the caregiver, especially unpaid female relatives, but also the thousands of low-paid women providing care in instititutions and homes, is thus a key issue for women.

Most unpaid family caregivers are midlife and older women. The caregiving role significantly affects labor force participation, as women try to juggle both work and family responsibilities. More than 20% of those caring for someone over age 65 work fewer hours or take time off without pay in order to meet caregiving responsibilities, and about 10% quit work altogether. This results in a loss of both present and future income, as pension and Social Security credits are forgone.

For those who are full-time caregivers, the burdens are very heavy. Housebound and isolated, exhausted, often depressed and financially depleted, they are likely to become ill themselves, or may abuse the person dependent on them. Without support for the caregiver, the result may well be two dependent adults instead of one. Thus while the primary focus of concern must be care of the frail elderly, public policy cannot ignore the needs of caregivers.

- **Long-term care is a women's issue because women have lower incomes than men; while they are more likely to need long-term care, they are less able to pay for it.**

In 1985, the median annual income for persons age 65 and over was $10,900 for men, and $6,300 for women. (The poverty level for an older person living alone was $5,156). Among the elderly, the poverty rate was almost twice as high for women as for men (women - 15.6%, men - 8.5%).

The caregiving role most women fill throughout their lifetimes is one reason for these income disparities. Every year spent at home rearing children or caring for elderly o disabled family members means another "zero year" when Social Security benefits are calculated; jobs quit to care for incapacitated spouses mean the loss of pension benefits and potential retirement savings.

If financing long-term care is privatized through long-term care insurance, older women may not fare well at all. Insurance companies are exercising great caution in marketing policies because of high potential claims and their lack of actuarial experience. Those most at risk of institutionalization--older women alone--may not be insurable, or may not be able to afford the premiums.

o **Long-term care is a women's issue because women are disadvantaged by current public mechanisms for financing long-term care.**

To the extent that older women need care for their prevalent chronic health problems or support in their role as caregivers for others, they are not well served by either Medicare or Medicaid.

Medicare is based on an acute medical model, with cure rather than care as its central focus. The new Medicare reimbursement system, with its incentives to providers to limit hospital stays, increases the burdens of caregivers when relatives are discharged much sicker than would have been the case in the past. In addition, getting home health benefits under Medicare has become increasingly problematic. Finally, Medicare pays nothing for long-term chronic care.

The Medicaid program of course does pay for long-term care, spending nearly 40% of its budget on nursing home care each year. But Medicaid's bias toward institutionalization and its eligibility rules and "spend down" process exact a heavy price from the elderly and from older women in particular. While eligibility requirements vary, all states require that the Medicaid applicant have few assets and extremely low income. For thousands of women whose husbands need nursing home care, this results in "spousal impoverishment."

RECOMMENDATIONS FOR CONGRESSIONAL ACTION

Mr. Chairman, we understand that this is the first in a series of hearings in which you will examine a number of pressing long-term care issues, including financing and quality assurance. Many of these issues are not likely to be resolved soon. However, there are some problems which can and must be addressed over the short-term.

These issues need Congressional attention both because of their compelling nature, and because of the expectations raised by current attention directed to "catastrophic health care" costs and coverage.

The elderly across the country hear that Congress and the President are going to do something to alleviate their fear of losing everything to a health care disaster. It's too bad you couldn't begin with a "truth in advertising" law on this subject, because proposals for "catastrophic coverage" that do not include long-term care are misnamed, intentionally or not.

In the remainder of our testimony, I will briefly discuss three concerns which we urge the subcommittee to address in the coming year: home health care restrictions, caregiver supports, and spousal impoverishment under Medicaid. The Older Women's League urges you to take action on these issues during the 100th Congress, whether or not long-term care provisions are ultimately included in a catastrophic care package.

Home Health Care Restrictions

Current health care financing systems provide few realistic alternatives to institutionalization in either a hospital or a nursing home.

Medicare's prospective payment system has resulted in earlier discharge with only limited home health care coverage in the community. To qualify for home health benefits in the Medicare program, patients must meet numerous tests, including that they are "homebound" and need "skilled care" on an "intermittent" basis. Medicare's interpretation of these regulations is increasingly restrictive and must, as a minimum, be restored to what Congress orginally intended.

Under recent interpretations, "homebound" has become "bedbound," so that patients who achieve any mobility within or outside the home (which paradoxically is the aim of the nursing services) are disqualified from Medicare payment. Similarly, if Medicare determines that the physician's order for some days of home nursing is more than "intermittent," payment for any home health service is denied.

In addition, if Medicare determines that a service rendered to the patient was less than "skilled," because they could have been performed by an untrained spouse or a neighbor (even if the patient lives alone), payment for all home health care is denied.

Finally, even if patients do qualify for Medicare coverage of home nursing care, they cannot receive additional home nursing from any other source, whether Medicaid, private insurance, or the patient's own funds. So if the patient receives Medicare nursing two days a week and pays privately for an additional day, Medicare denies coverage completely. The logic, though strained, is that if patients receive more nursing care than Medicare allows, they need more than "intermittent" care, and are therefore completely ineligible for home health care under current regulations. The result is that patients may not get needed nursing care, or are readmitted to the hospital or institutionalized in a nursing home at greater risk to their health and greater cost to payors.

The Older Women's League urges you to clarify the circumstances under which home health care ought to be available and to increase the access of Medicare beneficiaries to this essential service.

Caregiver Support

Even if patients satisfy all the restrictions for Medicare home health care, Medicare and Medicaid focus primarily on acute skilled nursing care in the home. Chronic nursing care, so-called "custodial" care, respite care, adult day care, and help with activities of daily living are not covered services under either Medicare or Medicaid.

Given this institutional bias, the financial and emotional pressures on patients who want to stay in their own or a relative's home and on caregivers who want to keep them there are enormous.

In recent years, there has been a number of legislative proposals focusing directly on caregivers. Expansion of the dependent care tax credit program to include workers with elder care responsibilities is an example of a welcomed change. Among current proposals, OWL supports legislation that would provide unpaid leave and job protection to workers caring for a seriously ill parent.

However, what most full-time caregivers say they need is not so much financial assistance but rather the provision of actual services and periodic relief from their caregiving burden. In this context, the notion that a tax break of several hundred dollars annually is a compelling "incentive" for a person to become a round-the-clock family caregiver is ridiculous.

In the private sector, there is a growing recognition of caregivers' needs. A number of employers are pioneering in the field of benefits to caregiving employees. Non-profit groups including churches and women's organizations have developed volunteer respite care and support group programs.

There remains a significant governmental role, however. If the pressure of the caregiving role is to be relieved and the institutional bias of the current health care delivery system is to be reversed, both Medicare and Medicaid must provide greater funding for alternatives to hospital and nursing home services, including expanded coverage for skilled home health care, chronic nursing care, palliative care, respite, hospice services and adult day care.

Spousal Impoverishment under Medicaid

As was noted above, "spousal impoverishment" results from the need to "spend down" assets in order to qualify for nursing home coverage under the Medicaid program. This unfortunate situation disproportionately impacts on women because they are more likely to be the married spouse living in the community and to outlive their institutionalized husbands. They are also less likely to have income in their own name that may be kept for living expenses.

It is estimated that 10% to 12% of nursing home residents have spouses living in the community. About half of nursing home patients are on Medicaid; if the ratio holds for married couples, up to 75,000 spouses of recent nursing home patients have lost their assets due to Medicaid eligibility tests.

TABLE 3 -- Persons in Homes for the Aged in 1980, by sex and marital status

	MEN		WOMEN	
Age	Married	Unmarried	Married	Unmarried
65-75	20,907	71,268	19,916	126,870
75-84	37,048	94,122	34,352	340,728
85+	23,450	77,508	16,664	370,124
Total	81,405	242,898	70,932	837,702

(Source: Census Bureau, PC80-2-4D [Oct. 1984], Table 17)

Under current Medicaid eligibility regulations, when one spouse applies for Medicaid coverage of nursing home care, the income and assets of both spouses are "deemed" available to pay for nursing home bills. The couple may keep their home, a car (maximum value-$4500) and $2550 in assets. All other assets must be spent down (ie, spent on medical bills) before the institutionalized person can be eligible for Medicaid.

At a cost of about $2200 per month for nursing home care, most couples will exhaust their resources within a year. The Medicaid program essentially strips the couple of the assets they saved over a lifetime, and leaves the spouse in the community without any savings.

In most states, after one member of the couple has been in the nursing home for a month, each spouse keeps the income in his or her own name. Jointly-held income may be deemed available to pay the nursing home bills. Women who do not have their own pensions (less than one in five does) or other income in their own name will be left with little monthly income for living expenses while the husband is in the nursing home. The community "spousal maintenance allowance" permitted by Medicaid is less than $300 per month in some states.

To remedy the tragedy of spousal impoverishment under Medicaid, the Older Women's League proposes two principles. First, the community spouse must retain an amount of monthly income sufficient to meet that person's fixed expenses. It is a cruel irony that the Medicaid system permits couples to keep their home, but denies them sufficient income to provide for taxes, utilities and upkeep. An appropriate federal floor of retained income will not leave the community spouse just barely above the poverty line; we advocate an amount equal to the median income of elderly American couples (about $1000 per month).

Second, community spouses must be allowed to retain assets sufficient to support themselves with dignity throughout the rest of their lives. In many cases, that is a period of 15 to 20 years or more. Savings equivalent to the median income of couples for a year or two would provide some of the security the elderly seek in "catastrophic coverage".

Even after "spousal impoverishment" is resolved, a further problem remains, which I will merely mention in closing. Medicaid eligibility does not guarantee a Medicaid bed. Discrimination against Medicaid patients in admission, transfer and discharge procedures is prevalent, and must be stopped. As part of an attempt to redress this problem, the Older Women's League has drafted a model state Medicaid anti-discrimination bill, which is submitted for the record.

We welcome the opportunity to work with you in the coming months to find solutions to these long-term care problems, particularly spousal impoverishment.

MODEL STATE MEDICAID ANTI-DISCRIMINATION BILL -- OLDER WOMEN'S LEAGUE, Jan. 1987

ANTI-DISCRIMINATION LEGISLATION

INTRODUCTION

That nursing homes prefer private-pay residents to Medicaid recipients is an undisputed fact. According to a 1984 report prepared by the Senate Special Committee on Aging, up to 80% of nursing homes which participate in the Medicare or Medicaid programs are reported to actively discriminate against Medicaid beneficiaries in their admissions practices. Likewise, the National Academy of Science's Institute of Medicine's Committee on Nursing Home Regulation has found evidence of discrimination to be "very strong." This Bill is designed to insure the Medicaid beneficiary improved access to long-term care facilities, stability of residency, and equality of services rendered.

A] DISCRIMINATION IN ADMISSION

A nursing home which receives payment from the state for rendering care to Medical Assistance recipients shall establish and maintain identical policies and practices regarding admission, transfer, discharge and covered services for all persons regardless of source of payment. Such facility shall:

1] Be prohibited from discriminating against persons who apply for admission to such facility on the basis of source of payment.

a] Except as otherwise provided by law, all applicants for admission shall be admitted in the order in which such applicants apply for admission.

b] **EXEMPTION** - Where more than [eighty] per cent of a facility's beds are occupied by Medical Assistance recipients, the facility may deny admission to current Medical Assistance recipients until such time as the facility's Medical Assistance occupancy rate shall fall below [eighty] per cent.

2] Maintain one list of names of persons seeking admission to the facility, which is ordered by the date of the request for admission. This information shall be retained for one year from the month that admission was requested. This dated list of applications shall be available at all times to any applicant, his or her bona fide representative, or any persons authorized to enforce these provisions.

3] Provide a dated receipt to each applicant for admission to its facility who requests placement on a waiting list stating the date and time of such request.

4] Give to all applicants for admission and post in a conspicuous place a notice informing applicants for admission that the facility is prohibited by statute from discriminating against applicants for admission on the basis of source of payment. Such notice shall advise applicants for admission of their right to apply for and to use medical assistance, and to receive prompt refund for any prior payments covered by medical assistance. Such notice shall advise applicants for admission of the remedies available under this section and shall list the names, addresss and telephone numbers of the ombudsman who serves the region in which the facility is located.

5] Disclose to members of the public, upon inquiry by telephone or in person, the following information:

(a) the daily rate charged private-pay residents by the facility
(b) the current availability of beds in the facility or/
(c) the number of persons currently on the facility's waiting list for admission
(d) the type(s) of care available at the facility

The facility may not inquire as to a prospective resident's financial condition or prospective source of payment before divulging this information.

6] Be prohibited from basing admission decisions upon assurances by the applicant, or the applicant's representative, to the nursing home, that the applicant is neither eligible for nor will seek Medical Assistance for payment of nursing home care costs.

7] Be prohibited from requiring or accepting from the applicant or resident, applicant's/resident's representative or relatives any payment, gift, donation, deposit, promise of payment, period of residence as a private pay patient, or any other consideration as a condition of admission, continued stay, or provision of care or service.

8] Be prohibited from denying admission to a facility solely because no third party is willing to accept personal financial liability for any of the facility's charges.

9] Be prohibited from refusing to accept retroactive Medical Assistance benefits.

10] Be prohibited from including in an admission agreement any clause or term that violates this act. A violation will be found despite a showing that the offensive clause has never been enforced.

11] Be prohibited from requesting or requiring an applicant, applicant's representative or relative to waive or forego any rights or remedies provided under state or federal law, rule or regulation.

12] Meet requirements of Title VI of the Civil Rights Act of 1964 and Section 504 of the Rehabilitation Act of 1973.

B] DISCRIMINATION IN TREATMENT, TRANSFER AND DISCHARGE

It shall be illegal for a nursing home which receives payment from the state for rendering care to Medical Assistance recipients to provide differential treatment on the basis of status with regard to source of payment. Differential treatment shall include:

(1) Charging residents who are Medical Assistance recipients for:

(a) Services which must be provided in order to comply with licensure or certification standards and that if not provided would result in a deficiency or violation by the nursing home.
(b) Services that are covered by the daily rate according to the agency providing payment.

(2) Using payment source as a basis in the assignment of rooms,except to the extent that private rooms are not included in the medical assistance plan; the assignment of staff to residents or groups of residents, or the allocation of facility resources in the provision of basic services to residents; or the restriction of residents' access to any room(s) or areas of the facility.

(3) Transferring or discharging a patient because of his or her status as a Medical Assistance recipient, or because of conversion to that status at any time after admission, **except** that a facility may transfer a resident from a private room to another room within the facility if Medicaid will not cover the cost of the original room.

(4) Requesting or requiring a resident, resident's representative or relative to waive or forego any rights or remedies provided under state or federal law, rule or regulation.

C] Remedies

For violations of any provision of this act, any or all of the following remedies may be pursued:

(1) An individual may bring an action in civil court to enforce any rights under this act. The court, upon finding violations of this act, shall award compensatory damages or $500 for each violation, whichever is greater, to the complainant(s). Such compensation shall be excluded from consideration as income or resources for the purposes of eligibility for medical assistance. If the violation is of a continuing nature, each day during which it continues shall constitute an additional separate and distinct offense. The court shall also award such equitable relief as is necessary and appropriate to effectuate the purposes of this act.

(2) The department may revoke, suspend, or take any other appropriate action against the license of a facility for the intentional violation of this act.

(3) A violation of this act shall constitute an unfair business practice, and shall be enforceable by the office of the Attorney General under the appropriate laws of this state.

STATEMENT OF STANLEY J. BRODY, J.D., M.S.W., PROFESSOR OF PHYSICAL MEDICINE AND REHABILITATION; AND DIRECTOR OF THE RESEARCH AND TRAINING CENTER FOR REHABILITATION OF ELDERLY DISABLED INDIVIDUALS, UNIVERSITY OF PENNSYLVANIA, PHILADELPHIA, PA

Dr. **Brody**. Thank you very much, Senator. My name is Stanley J. Brody. I am Professor of Physical Medicine and Rehabilitation and Psychiatry at the Medical School and Professor of Health Care Systems at the Wharton School at the University.

I want to thank you for inviting me to testify. This continues a dialogue that we have had with the Senate that goes back almost 20 years. Chronic disability requires long-term sustaining continuous care. It results in some older people being dependent on others for assistance in their daily lives for long periods of time; and as such, it is the major catastrophic health need of an aging society, affecting not only the disabled elderly but their families as well. Moreover, it is an even greater catastrophe affecting more the elderly and their adult children than the relatively fewer episodes of prolonged acute hospital stay, currently being addressed and identified as catastrophic care.

There is a common misperception about what the respective roles of Government and the family should be in helping these disabled elderly. And certain facts about the disabled elderly and their families are no longer a scientific issue, even though it seems difficult for the public and policy makers to accept them. For example, families of disabled older people have been dependable in providing transitional care—that is, from the hospital to the community and long-term care.

As the informal system of care, families provide the vast majority of medically related supportive health and social services. Less than 15 percent of helper days of care to old people needing help in the activities of daily living (ADL)—bathing, feeding, dressing, mobility transferring, and toileting—are provided by the formal or nonfamily system. Only four percent of the elderly who need ADL assistance have any part of it paid for by Government.

Services from the formal support system, including Government, do not encourage families to shirk caregiving but do complement and supplement family services. Families take the disabled elderly into their homes when they are no longer capable of independent living. Families do not dump disabled relatives into institutions but rather continue care for years at substantial economic and social costs to themselves and to society.

Families respond in emergencies, provide intermittent care, implement rehabilitation procedures; and I would say in passing that we couldn't manage rehabilitation without families with older people to give emotional and service support.

Families mobilize and coordinate informal and formal systems. They are the real case managers. Families suffer strain; and as many as 50 percent experience significant mental health systems. And a major loss suffered by family caregivers—about which information has recently emerged—is the opportunity costs incurred when spouses and adult children leave the work force—and usually we are talking about women here—to focus on the caring responsibility.

Despite extensive data to the contrary, the elderly and their families deny the probability of disability as a normative problem to be anticipated and insured against. In this avoidance of the problem, they are joined by the insurance company and certainly by Government, who regard long-term care as a bottomless pit.

New data suggest that long-term care has definable dimensions and that calibrating the need for services in terms of ADL would provide the framework needed to define the insurable task. And we have explained that in detail in our testimony; it is not a bottomless pit.

Older people do not expect to become disabled; older people think they are covered by Medicare or Medigap policies for catastrophic long-term care. Medicap marketing misleads older people into believing that they have catastrophic long-term coverage; and I might say we are seeing a good example of that being done today publicly by this Administration. The current additional Medicap policy proposal providing protection against catastrophic extended hospital stays is described by the President as the new coverage that will give the elderly, and I quote: "That last full measure of security that fights the fear of catastrophic illness."

These kinds of reassurances for the elderly reinforce their belief that they are indeed covered for the overriding catastrophe, that of needing long-term care. They reinforce the media presentation by other well-known personalities on behalf of insurance companies that lull the elderly and their families into a false sense of security and discourage them from seeking the true "last full measure of security against the risk of catastrophic long-term care."

In short, protection for long-term care needs would help families to do what they have been doing and want to do to help the elderly and would prevent family breakdown that results from excessive strains so many experience. The issue in terms of public policy is to protect the aging's family as well as the aged disabled individual from catastrophic need.

It is a publicly insurable risk.

Senator MITCHELL. Thank you very much, Dr. Brody.

[The prepared written statement of Dr. Brody follows:]

Testimony on

LONG-TERM CARE: OVERVIEW

by

DR. STANLEY J. BRODY

Before the United States Senate
Committee on Finance Sub-committee on Health
24 February 1987

My name is Stanley J. Brody. I am Professor of Physical Medicine and Rehabilitation in Psychiatry at the Medical School and Professor of Health Care Systems at the Wharton School of the University of Pennsylvania. I am also Director of the Research and Training Center for Rehabilitation of Elderly Disabled Individuals supported by the National Institute on Disability and Rehabilitation Research.

Chronic disability requires long-term, sustained, and continuous care. It results in some older people being dependent on others for assistance in their daily lives for prolonged periods of time. As such, it is the major catastrophic health need of an aging society, affecting not only the disabled elderly but their families as well.

Moreover, it is an even greater catastrophe, affecting more of the elderly and their adult children, than the relatively fewer episodes of prolonged acute-care hospital stay currently being addressed and identified as catastrophic care.

There is a common misconception about what the respective roles of government and the family should be in helping the disabled elderly. Certain facts about the disabled elderly and their families are no longer at scientific issue even though it seems difficult for the public and policy makers to accept them:

- Families of disabled older people have been dependable in providing transitional (from the hospital to the community) and long-term care.

- As the "informal" system of care, families provide the vast majority of medically-related supportive health and social services.

- Less than 15% of "helper days of care" to older people needing help with activities of daily living (ADL, i.e., bathing, feeding, dressing, mobility, transferring, and toileting) are provided by the "formal" or non-family system.

- Only 4% of the elderly who need ADL assistance have any part of it paid for by the Government.

- Services from the formal support system (including Government) do not encourage families to shirk care-giving but do complement and supplement family services.

- Families take the disabled elderly into their homes when they are no longer capable of independent living.

- Families do not "dump" disabled relatives into institutions but rather continue care for years at substantial economic and social cost to themselves and society.
- Families respond in emergencies, provide intermittent care, implement rehabilitation procedures, and give emotional support.
- Families mobilize and coordinate informal and formal services (i.e., case management).
- Families suffer strain and as many as 50% experience significant mental health symptoms.
- A major loss suffered by family caregivers, about which information has recently emerged, is the opportunity costs incurred when spouses and adult children leave the work force to focus on the caring responsibility.

Despite extensive data to the contrary, the elderly and their families deny the probability of disability as a normative problem to be anticipated and insured against. In this avoidance of the problem, they are joined by the insurance industry and Government who regard long-term care as a bottomless pit.

New data suggest that long-term care has definable dimensions and that calibrating the need for services in terms of ADL would provide the framework needed to define the insurable risk. It is not a bottomless pit.

Barriers to developing long-term care insurance are that:

- Older people do not expect to become disabled.
- Older people think that they are covered by Medicare or medigap policies for catastrophic long-term care.
- Medigap marketing misleads older people into believing that they have catastrophic long-term coverage.
- The current additional medigap policy proposal providing protection against catastrophic extended hospital stays is described by the President as the new coverage that would give the elderly "that last full measure of security that fights the fear of catastrophic illness."

These kinds of reassurances for the elderly reinforce their belief that they are indeed covered for the overriding catastrophe, that of needing long-term care. They reinforce the media presentations by well-known personalities on behalf of insurance companies that lull the elderly and their families into a false sense of security and discourage them from seeking the true "last full measure of security" against the risk of catastrophic long-term care.

In short, protection for long-term care needs would help families to do what they have been doing and want to do the help the elderly, and would prevent family breadown that results from the excessive strains so many experience. The issue, in terms of public policy, is to protect the aging family as well as the aged disabled individual from catastrophic need. It is a publicly insurable risk.

CONTINUITY OF CARE: THE NEW-OLD HEALTH REQUIREMENT

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CONTINUITY OF CARE: THE NEW-OLD HEALTH REQUIREMENT

Chronic illness has overtaken acute illness as the major health concern and as the prime cause of dysfunctioning for people of all ages. This finding was thoroughly documented almost 30 years ago by the Baltimore study of the Commission on Chronic Illness (1957) under the leadership of Abe Lilienfeld, and it has been confirmed repeatedly by the annual morbidity and mortality reports of the National Center for Health Statistics (Brock and Brody, 1985; Minaker and Rowe, 1985; U.S. DHHS, 1984).

Continuity is a necessary component of care for chronically ill patients. It is inherent in the goals of chronic care: to restore and maintain the individual's highest level of functioning and independence over extended periods of time. Advances in surgical and medical techniques have allowed the survival of many more congenitally impaired infants, who then require supportive health services over their lifetimes. The same scientific advances have allowed those who are congenitally and traumatically impaired to survive to old age. The cumulative effects of morbidity, combined with the social and economic decrements of age, result in approximately 30% of those over 65 years of age requiring some assistance to function in their daily lives (Brody, 1973). About 18% of the elderly require major help from another person and about 5% are totally disabled and housebound (Brody and Persily, 1984). An additional 5% of the aged are institutionalized.

Requirements for continuity of care thus arise from disease, injury, and the processes of aging. Because of the increase in the population over 65 years of age, and particularly in those over age 85, the magnitude of such care has become substantial. This increase has tended to distort the projections of demand on the acute- and long-term care subsystems that make up the health delivery system.[1] Currently, acute-care commands the major portion of the more than $400 billion expended annually on health care in the United States. The societal focus on high-techology medicine, combined with the denial of chronic disability as an expectable condition for which provision must be made, continues to preserve the imbalance in the allocation of resources between acute and chronic illness (Vladeck, 1985). These perceptions have tended to overwhelm policy discussions and instill a general sense of pessimism about our ability to provide appropriate long-term care for chronically disabled persons. An understanding of the diversity and growth of this population is basic to clarifyingthe possible contributions of various components of the health system, social as well as medical, toward the solution of the need for continuity of care (Brody and Magel, in press).

Traditionally, continuity of care, if it was considered at all, was thought of in medical terms. The Robert Wood Johnson Foundation (1986), reporting on the Municipal Health Services Program, defined continuity of care as "the co-ordinated, uninterrupted, and complete succession of medical care events consistent with the medical needs of the patient, which is generally possible when visits are to one medical provider, health clinic, or physician, rather than many providers" (p. 14). Others have described it, as we do here, in health terms that address psychosocial services in addition to medical care. The focus of care shifts over time between medical and social services in response to the changing health needs of the elderly individual and the informal support system. Continuity of care embraces all providers, with many of the services delivered in concert or separately as required.

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[1] See, for example, Census Bureau predictions of 2.2 million SNF beds required by year 2000 and "will more than triple to 5.4 million over the next 50 years" (U.S. Senate, 1984).

The current market for continuity of care services involves two different client groups: those who require temporary support, or short-term long-term care (STLTC), and those in need of permanent or extended support or long-term long-term care (LTLTC). The dual nature of the market is suggested in part by the elderly's short-term use of skilled nursing facilities (SNF) and home health agencies (HHA). Among the elderly persons who experienced SNF stays in 1977, 53.7% (600,000 admissions) stayed less than 90 days whereas 46.3% stayed 90 days or more (U.S. DHHS, 1979). Over one million older people use Medicare-reimbursed HHA services annually (HCFA, 1985). Medicare funding of this service indicates that this, too, is a STLTC experience, since in practice Medicare rarely pays for extensive services over time, even if it is permitted legislatively.

The first group, "the temporarily needy, frail elderly," either are discharged from the SNF to their homes (39.8%), are admitted to the hospital (23.5%), or die (21.2%). The same duality of short-term and long-term utilization of SNFs may be observed in home care services. Palmer (Vogel and Palmer, 1983) classified home care as "intensive" when it is aimed at reducing hospital stays and features heavy medical or nursing involvement and high-technology apparatus in the home. Longer term home care may be classified as "basic" (maintenance and/or personal care) when it is designed to sustain dependent people in the community and avoid institutionalization.

Those in the second group are the "permanently disabled, frail elderly." They are not likely to return to their homes from the SNF, but those who do are likely to require continuous long-term service that is socially-oriented as compared to the more medically-oriented STLTC services. Furthermore, the process of becoming needful of support is not necessarily abrupt, but may happen gradually as the older person remains at home in the community and experiences changes in levels of functioning requiring LTLTC support services. Indeed, it is well established that there are twice as many disabled elderly living in the community as live in SNFs, many of these elderly will end their lives as community residents (Brody, Poulshock, and Masciocchi, 1978).

The continuity concept is implemented through (a) a case management service (sometimes called "service management" or "patient care coordination"); (b) modification of existing services and nursing practices provided to the patient in the acute stage of illness; (c) an integrated system of postacute "step-down" services (i.e., STLTC); and (d) an integrated LTLTC system that includes all segments of institutional, community, and in-home services.

Case management monitors, mobilizes, and coordinates services for the patient and the family from the moment of admission to the hospital (or, in selected cases, prior to admission). To be distinguished from discharge planning, case management follows through the entire period of inpatient hospital stay and continues into postacute hospital step-down care until the elderly patient is established at home (with or without home care services). Some STLTC patients may go directly into LTLTC with maintenance services in the community, at home, or by means of permanent placement in a long-term care institution. Within the hospital setting, case management is responsible for care beyond the acute inpatient experience (i.e., beyond the hospital walls in time and place).

From the experience of the 24 hospitals participating in the Robert Wood Johnson Foundation project, "Hospital Initiatives for Long-term Care," it is estimated that 10% to 18% of elderly patients may require case management services within the acute-care setting. Many Medicare beneficiaries require services for a relatively short period of time (less than 90 days, posthospital) as a transition from the hospital to the community.

A minority may continue beyond the transition period directly into LTLTC (Robert Wood Johnson Foundation, 1982).[2]

Modifications of existing services available to the acute stage elderly patient within the hospital are also necessary. These might include rehabilitation teams, placement of geriatrics-trained nurses on units where those patients are admitted, an active geriatric physician consultant program, and design modifications of units and rooms. In the last of these, redesign and reconstruction would be aimed at maintaining the self-reliance of the older patient during the hospital stay.

SHORT-TERM LONG-TERM CARE

At least 1.75 million elderly are already involved in STLTC--either short-term stays in SNFs or short-term Medicare-reimbursed HHA services. Usually these services follow an acute-care hospital discharge and are for less than 90 days. The need for these services is frequently terminated by the patient's ability to function independently or through the mobilization of an adequate informal support system.

STLTC or step-down services may include inpatient and outpatient rehabilitation services, convalescent care provided through SNFs, rehabilitation hospital day care, hospice care, home health care, and other community programs (e.g., meals-on-wheels). A model STLTC system is shown on the next page (Figure 1).

Hospitals are an appropriate setting for STLTC service, although other settings, such as ambulatory geriatric care centers, are evolving which provide many of these services. SNFs, too, are expanding their services into the community, usually by offering day hospital, day care, or respite services. Hospitals are able to provide a full range of professional and technical resources, emergency care, and specialty services. They are experienced in the management of multidiscipline, multispecialty, and multilevel care. Accordingly, they have the potential to manage an STLTC system.

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[2] "The Program for Hospital Initiatives in Long-Term Care . . . offered grants of up to $800,000 to 23 not-for-profit, voluntary or public hospitals to improve long-term care services in their communities for a defined population of elderly persons.

The primary objective of the Program is to encourage the development of model projects which will demonstrate that hospitals can develop comprehensive programs to better meet the health care needs of the elderly. Under the Program, elderly persons in need of long-term care will be provided with an array of institutional and home-based services, coordinated and managed by selected hospitals. These services may be offered either by the hospital directly or through contracts with outside agencies.

This Program seeks to address two areas critical to promoting an acceptable quality of life for the aged. First is the need for elderly persons to retain maximum independence and functional ability and to avoid unnecessary use of costly hospital and nursing home services. Second is the need to improve the capabilities of physicians, nurses, and other hospital staff to care for the elderly in all areas of hospital activity including emergency, outpatient, acute inpatient, and long-term care services" (p. 3).

Figure 1

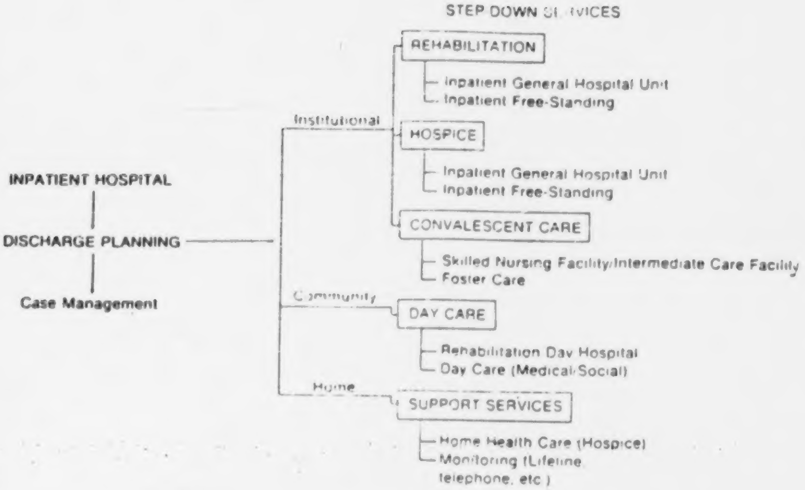
STEP DOWN SERVICES
REHABILITATION
Inpatient General Hospital Unit
Inpatient Free-Standing
Institutional
HOSPICE
Inpatient General Hospital Unit
Inpatient Free-Standing
INPATIENT HOSPITAL
DISCHARGE PLANNING
Case Management
CONVALESCENT CARE
Skilled Nursing Facility/Intermediate Care Facility
Foster Care
Community
DAY CARE
Rehabilitation Day Hospital
Day Care (Medical/Social)
Home
SUPPORT SERVICES
Home Health Care (Hospice)
Monitoring (Lifeline telephone, etc.)

FIGURE 1. A model of a hospital based system of short term long-term care

Source: Brody, S. J., and Magel, J.S. "DRG: The Second Revolution in Health Care for the Elderly," JAGS. 1984, 32(9): 678.

Although continuity of care may be inherent in the goals of chronic care, it is an economic necessity for the acute-care system in providing for the geriatric patient under Diagnosis-Related Group (DRG) Medicare regulations. The essence of continuity of care is timely intervention with appropriate levels of relevant services. Punctual hospital discharges may be achieved by focusing on improving the elderly patient's level of functioning and by mobilizing the formal and informal systems so that the patient moves efficiently and effectively into a supportive post-acute environment. To some degree this is a reformulation of the idea of progressive patient care by the hospital, a process proposed in the 1950s by then-Surgeon General Leroy Burney (1958), who described a series of services:

> intensive care, intermediate care, self-care, long-term care, home and ambulatory care . . . Adjoining the hospital would be a nursing home type of facility for long-term patients. All of these units would be linked to a home program and ambulatory services. Rehabilitation services would be available for each "progressive" area (p. 69).

At the same time, in Oxford, England, the Cowly Road Hospital under the leadership of Lionel Cosin (1967) was providing three descending levels of care within the hospital, followed by the patient's attendance at a day rehabilitation hospital on the same campus, and thereafter continuing with care at home by the visiting nurse service.

Continuity of Care

The elderly are now recognized by hospitals as an important and growing market for their services. Conversely, hospitals are the most important community agency for the aged, 20% of whom use the hospital at least once during a year for an inpatient stay and another 30% for outpatient services. Older people now account for almost 27% of all hospital admissions and 40% of all patient days of care. Hospitals thus are in a pivotal position, servicing more elderly people (5 million inpatients with 10 million admissions; 10 million outpatient utilizations) than any other community agency (Brody, 1982).

Hospitals not only have a long history of providing acute-care services to the elderly, they also participate in long-term care service through the discharge planning function. Nationally, nearly one-third of all initial admissions to SNFs are from general or short-stay hospitals (Brody and Magel, 1984). It is alleged that the onset of DRGs has increased this flow, although at this writing data are not available. It is also alleged that the intensity of the level of services required in short-term utilization of HHAs and SNFs has increased as a result of DRGs. This change may be due to placement in more appropriate care settings as much as to the influence of DRGs, or it may result from a combination of the two factors.

Hospital-based or -related STLTC revolves around step-down services designed to meet the transitory medical and health needs of older persons. The goal is the timely restoration of the individual to community living through improvement of the level of patient functioning and/or the mobilization of personal and environmental resources. Some of the findings from the data gathered at the Piersol Rehabilitation Center, under the auspices of the Rehabilitation Research and Training Center in Aging, suggest that a major way of avoiding a long-term placement in an SNF is by means of timely STLTC services (Masciocchi, 1985). These services allow for attainment of the STLTC goal by mobilizing the family support network and improving the elderly patient's level of functioning.

STLTC patient care may be financed by Medicare, private health insurance, or consumer payments or through the trade-off of dollars recovered by hospitals under DRG reimbursement because of early acute-care discharge made possible by use of STLTC services. If DRG reimbursement were treated by hospitals as a prospective payment, not only for the inpatient stay but for transition to the community as well, continuity of care would be enhanced, as would the hospitals' economic viability. Because the hospital experiences its greatest cost during the early days of an admission, the trade-off of DRG dollars for a shorter stay is not an even day-for-day exchange.

Development of step-down services fosters the verticalization of health care. Traditional boundaries are crossed when services and service settings are organized through service (case) management to respond over time to the changing hierarchy of patient care needs and those of the supporting family. Such an organization and monitoring of services can assure continuity of care and timely discharge from the acute-care setting. The constellation of resources required for patient care should be identified through patient assessment and the system of care (STLTC services) should include community- as well as hospital-based services.

Hospitals have approached the organization of STLTC services in a variety of ways, depending on the resources available in the community, the way these are used by the neighborhood or ethnic groups, and the nature of their organization. For example, churches occupy an important role in the lives of some groups and provide care through strong informal support groups. Similar organizations of care may be evident through unions or condominiums. Markedly, life care communities are assuming such a role, and early hospital discharge of their residents is a recently observed phenomenon.

Some hospitals have well-developed relationships with health or social agencies. These agencies act as intake stations for the case management system. Others, through either joint venture or other arrangements, collaborate with the hospital. Area Agencies on Aging (AAAs) have played a prominent role in working with hospital case management programs. In some communities hospitals are more self-contained and directly provide most of the STLTC services.

The prominence of any one service in the course of treatment may change as the patient progresses through levels of function and stages of care, requiring mobilization of different resources. As a center of community health care resources, the verticalized hospital may act as a catalyst for system development and organization, providing these resources directly or through referral. Hospitals that have recognized this possibility have already reorganized as "health centers." It is suggested that the hospital's role should be limited to STLTC and that the less medically- and more socially-oriented LTLTC responsibility may fall more appropriately within the purview of a community agency such as an AAA, an HHA, or an SNF.

Many hospitals are already actively involved in long-term care services (Brody and Persily, 1984; Campion, Bang, and May, 1983; Rocheleau, 1983; Vogel and Palmer, 1983). Their involvement has included the development of step-down services and the acquisition or construction of SNF and rehabilitation facilities. For example, more than 1,500 hospitals already offer HHA services, and as many as 1,200 provide some form of SNF care. In addition, the flow of LTLTC patients between the SNF and the hospital is becoming more intensive, creating what Robert Kane has described as a "ping-pong" effect (Lewis, Cretin, and Kane, 1985). Some have observed that SNFs often send dying residents to the hospital to avoid the paperwork surrounding death in our society.

The capacity of the hospital or any other agency to provide STLTC is determined in part by the ability of the market to finance services. Medicare, through DRG-based prospective reimbursement, may support the growth of hospital-based long-term care services, should the hospital opt to use excess funds for that purpose. Nearly all persons 65 years of age and over are eligible for health insurance coverage under Medicare and benefit significantly from that program for catastrophic acute-care. DRG-based prospective reimbursement addresses the structure of health care delivery and provides a means of reallocating acute-care resources to alternative care delivery systems. however, such restructuring is dependent on the hospital chief executive officer's vision of health care and willingness to use excess funds to expand STLTC services.

Under DRG-based prospective reimbursement, hospital revenues are tied to the number and distribution of patients across DRGs and the hospital's success in turning over inpatient beds rapidly. Payment is fixed by diagnosis, and actual lengths of stay have no direct bearing on the Medicare payment received for patient care. Inpatients whose stays are less expensive than the assigned DRG limits represent revenue gains; inpatients whose stays are more costly than the assigned DRG limits represent revenue losses. The system places hospitals at risk of inappropriate utilization, but it also provides a means by which efficient facilities can accumulate funds for investment.

To the extent that step-down services are developed, discharge options are expanded, thus providing hospitals with a means of accelerating the movement of patients out of hospital beds in a responsible manner. Revenues realized by more efficient patient care may be channeled into the development and support of step-down services. By providing a less-intense, less-restrictive level of care than that of acute-care, step-down services answer the short-term transition needs of the recovering elderly patient. For the hospital, these services represent a source of revenue independent of inpatient admissions and outside of DRG review. Many of these services may be paid for by the existing Medicare mechanism. For example, inpatient rehabilitation beds, day rehabilitation hospital care, and HHA services are covered under the Medicare program. Short-term SNF stays may also be covered. Foster home care may be supported through Social Security Title XX (Social Services) or through Supplemental Security Income (SSI, Title XVI of the Social Security Act). The decrease in acute-care inpatient days has made available a substantial number of excess inpatient beds and space that could be used for STLTC purposes, such as SNF, convalescent care, respite care, or rehabilitation.

LONG-TERM LONG-TERM CARE

It may be that we have overestimated the need for LTLTC services (Weissert, 1985). Much of what has been characterized as long-term care has been and increasingly is STLTC, that is, long-term care for a short time period. Furthermore, while the number of SNF beds has increased by one-third during the last 10 years, the number of elderly residents has remained relatively stable--this during a period when the elderly population increased in number by four million and the numbers of those over 85 years of age doubled. The increase in institutional residents was accounted for by the younger disabled, primarily mentally retarded persons who were deinstitutionalized from state institutions to intermediate care facilities, which are usually grouped under the SNF rubric. In addition, the elderly appear to be more healthy and more socially and economically intact as new cohort groups join the ranks of those over-65 years of age.

The need for long-term care services for those chronically disabled people who require services over time is not static. The passage of time may alter the nature or the intensity of the needed service, or the need for services may be temporarily eliminated or decreased. Thus a long-term care system must provide a broad array of services and, in addition, a mechanism for helping the disabled elderly and their families to utilize the variety of services appropriately at different times and under different conditions. Figure 2 (next page) suggests such an LTLTC paradigm. The model LTLTC system proposes a case or shared management focus to ensure that the varying needs for services of different intensity are available from the array of services listed. To aid the "manager," assessment services are provided not only at intake into the system but at whatever time the need for a reevaluation occurs because of a change in the elderly client's condition, in the informal support system, or in the environment. Again, the purpose is to provide for continuity of care. In contrast to the acute phase of the aged patient's treatment, which is supported by third-party payment and the focus of media attention, LTLTC is given short financial shrift by the formal support system and little attention from the media. Medicare, Medicaid, Blue Cross, and commercial insurance carriers afford scant funding for long-term care services. A few experimental models, such as the four social/health maintenance organizations (SHMOs) and the channeling demonstrations, are being developed with federal and local support. Commercial insurers are making some tentative, cautious offerings. More promising are the life care communities which make vailable continuity of care services for those who are able to afford the initiation and maintenance fees.

Figure 2

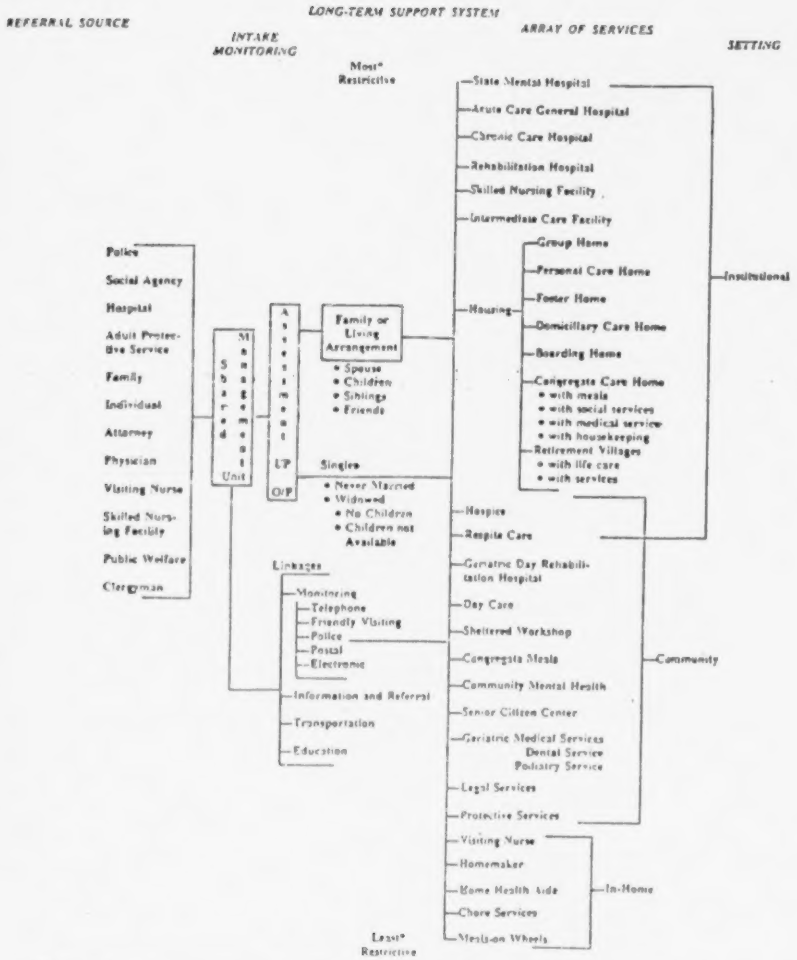
REFERRAL SOURCE
LONG-TERM SUPPORT SYSTEM
INTAKE MONITORING
ARRAY OF SERVICES
SETTING
Most* Restrictive
Police
Social Agency
Hospital
Adult Protective Service
Family
Individual
Attorney
Physician
Visiting Nurse
Skilled Nursing Facility
Public Welfare
Clergyman
Shared Management Unit
Assessment
I/P
O/P
Family or Living Arrangement
• Spouse
• Children
• Siblings
• Friends
Singles
• Never Married
• Widowed
• No Children
• Children not Available
Linkages
Monitoring
Telephone
Friendly Visiting
Police
Postal
Electronic
Information and Referral
Transportation
Education
State Mental Hospital
Acute Care General Hospital
Chronic Care Hospital
Rehabilitation Hospital
Skilled Nursing Facility
Intermediate Care Facility
Housing
Group Home
Personal Care Home
Foster Home
Domicillary Care Home
Boarding Home
Congregate Care Home
• with meals
• with social services
• with medical service
• with housekeeping
Retirement Villages
• with life care
• with services
Institutional
Hospice
Respite Care
Geriatric Day Rehabilitation Hospital
Day Care
Sheltered Workshop
Congregate Meals
Community Mental Health
Senior Citizen Center
Geriatric Medical Services
Dental Service
Podiatry Service
Legal Services
Protective Services
Community
Visiting Nurse
Homemaker
Home Health Aide
Chore Services
Meals-on Wheels
In-Home
Least* Restrictive

Figure 2. Inventory of Recommended Available Services, Appropriate to a Long-Term Care/Support System

* The classification of from most to least restrictive is a general view of services and may vary within each service.

Source: Brody, S.J. and Masciocchi, C. "Data for Long-Term Care Planning by Health Systems Agencies", _AJPH_, 1980, _70_(11), 1194-1198.

CONCLUSION

Thus, auspices for STLTC and LTLTC services are subject to the initiatives of the marketplace. Hospitals may be, and many already are, involved in not only STLTC but LTLTC as well. So, too, are SNFs, a few of which also offer acute services. Community agencies have moved to accept responsibilities for long-term care through "channeling" projects, SHMOs, and other initiatives. AAAs are prominent in this regard. Many proprietary and voluntary efforts are being undertaken to provide continuity of care through a vertical health system that includes acute-care facilities, SNFs, and HHAs as direct services. Some proprietary and voluntary organizations are experimenting with funding, in addition to arranging for the provision of the array of services.

The development of continuity of care as an appropriate response to the health needs of the elderly is hampered by the lack of a national health policy that goes beyond acute medical care. The federal government has asserted that long-term care is primarily the responsibility of the states. Band-aid federal approaches limited to "demonstrations" lasting more than one-and-one-half decades testify to the ineffectiveness of national health policy. States are devising methods to limit their expenditures for LTLTC. Consequently, there has been significant growth in voluntary and proprietary sources providing continuity of care through an array of STLTC and LTLTC services for those elderly who are able to pay.

As the cohorts of older people change successively, the one-third who seem to be economically secure will increasingly have the continuity of care they require made available from the private sector. Those concerned with the delivery of health care to all of the elderly have the task of clarifying and publicizing the need for continuity of care, and developing resources that will make such care accessible and available to all, regardless of income.

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Senator MITCHELL. We will now proceed to questioning. We will have five minutes per Senator in the order that the Senators appeared. Ms. Blood, on page 1 of your statement, you refer to a survey conducted for the AARP by the Daniel Yankelovich group. And you said that more than three out of four Americans in all age groups said they favor expansion of Medicaid to include the costs of long-term health care.

Ms. BLOOD. That is correct.

Senator MITCHELL. Did that survey also ask people whether they have any preferred method of paying for that; and do you have any comments on that? How would you finance the expansion of the Medicare program to include such costs?

Ms. BLOOD. The survey did not specifically address that, as far as how would we finance it. I think that, as we mentioned in our testimony, it has to be a combined effort of both public and private focus on the problem and that the private element isn't alone going to be an answer. Private insurance is going to leave a whole element of people that cannot afford it, and that is where the Government efforts would have to be coordinated with.

I do not have a suggestion, nor have I heard from the AARP any specific suggestion as to how that coordination would take place.

Senator MITCHELL. May I ask the other members of the panel to comment on whether they favor expansion of the Medicare program to include long-term nursing care and, if so, how do you propose that it be paid for? Mr. Clayman, do you have a comment on that?

Mr. CLAYMAN. We have raised some very specific suggestions, not that broadly.

Senator MITCHELL. Right.

Mr. CLAYMAN. Obviously, it would be magnificent if we had the capacity to do that exactly. I have no great wisdom on how to do it, except generally to understand that any society worth its weight that has the kind of industrial background that we have, that has the economy we have—in spite of our problems at the moment—that can't do it is failing somehow. And frankly, to express a heretic notion, perhaps the only real measure that will accomplish the job is a national health comprehensive program that affects all of our society, not only the old, but the young and the middle-aged. All of you know about this issue in Congress; you have been playing around with it—and I don't mean you specifically—with this issue for many years to know very well that the rest of this world—the rest of this total world, meaning the industrial nations—have adopted in one form or another this program, including Canada, and doing immensely well with it.

One quick observation. If you want to test how a program of this nature works in a country, you approach the politician; he knows the temper of the times, the temper of the people. And there isn't a single government—conservative or liberal or what-have-you—that would dare do away with any of their programs of this sort—a national comprehensive health program—in the whole world. That includes, for example, the English or the British Government. The Premier has not found fault with their program. The Canadians have not found fault with their program.

No politician has found fault with this program—here or there, little minor things—in the whole world. So, since I don't have an accurate answer in terms of what new approaches—how much would it cost and all the rest—I am prepared to suggest that ultimately, but it won't come in my time—but ultimately—those sitting where you are sitting now will come to that realization, as our friends and neighbors, the Canadians, have. Now, that is a long opportunity that you gave me that I didn't want to miss.

Senator MITCHELL. And you didn't. [Laughter.]

We will get to Ms. Jaycox and Dr. Brody later. My time is about up; so, we will go to Senator Packwood now.

Senator PACKWOOD. Dr. Brody, I had a chance to read your entire paper while you were testifying. And I am intrigued, if I understand what you are driving at. You are saying that what you call short-term long-term care properly handled may negate the necessity for lots of long-term long-term care. Did I read it correctly?

Dr. BRODY. That is correct. As you well know, the work on the channeling projects and all the other community projects have really not resulted in anything significant in terms of the reduction of institution utilization.

The one point where it is at risk—and I think Senator Bradley knows this very well from Morristown, where we have a project, the Robert Wood Johnson project there—that the real point at issue is when a person leaves the hospital.

For example, in my shop, in which we deal with rehabilitating at the hospital at the University of Pennsylvania, with very, very disabled older people—bilateral and amputees, with pacemakers, and on dialysis—whom I have to tell you walk home. And we only have a record of five percent of our population going to nursing homes. So, if the proper intervention is done at that point, I think it will resolve a lot of the long-term though not substantial.

Sooner or later, if you have an Alzheimer's situation, if you have more than five ADLs, a nursing home becomes appropriate because the cost to the family is just too much. But in terms of the small group of people—the marginal people—who really don't belong in nursing homes or could be avoided going to nursing homes, for that group that is the point of intervention.

Senator PACKWOOD. Let me ask you a further question, and it is a follow-up on what the chairman was asking. To the extent that you are going to have to have some long-term care, that short-term long-term care, as well managed as it may be, will not obviate all of the problems, is there any way that the private insurance industry can afford to provide that without some kind of conditions to the insurance spread over a large group? Or are they simply going to be subject to adverse selection, and they won't be able to provide it for a reasonable fee for those who need it?

Dr. BRODY. For a whole variety of reasons, Senator, I am convinced—I chair the committee for the American Hospital Association on Long-Term Care Insurance, and it started convinced that private insurance was the way and ended up just the other way around. As long as we are dealing with a group of people whom we are asking to insure against the very thing they don't want to happen, you can't rely on that kind of voluntary insurance.

In addition to which, as you know, aside from the Baucus amendment, insurance companies have a roll-up of 50 percent up front. And under those circumstances, it just won't work. So, the need for the universality of the coverage really mandates a public approach, and I have come to that very begrudgingly; but I see no other option.

Senator PACKWOOD. Let me ask you this, which is a fear that bothers everyone in Congress; and that is the fear of utilization that we did not foresee—an extraordinary cost that we didn't foresee. If you have universal coverage, and we will say it is an expanded Medicare program, and we will charge everybody from the time they go into the work force onward, if you did not have adequate short-term long-term care, if everyone knew that at the end of the road there was a nursing home fully paid for, is there any way that we can adequately guess what the cost might be?

Dr. BRODY. I had the same question asked me, I think about 10 years ago, by a Senator from Florida—there goes my Alzheimer's——[Laughter.]

But that is long-term memory; so it is all right. It is very difficult to hazard that kind of a guess. You can't predict. Suppose we resolve Alzheimer's within sight of a 10-year period, which is conceivable now that we have identified some of the key elements in the disease. So, that would completely change our expectation.

And let me give you the other side of the picture. We don't even begin to understand what the million and a half carriers of AIDS are going to result in as they age and what their need for nursing homes is going to be. So, it is very difficult to sit here and start to make a prediction.

And I think Wilbur Cohen was very smart in 1964 and 1965 in not predicting anything around the long-term care issue. It is very unpredictable. On the other hand, you can safeguard by, I think, requiring four or five ADL deficits before you start a long-term care support program.

Senator PACKWOOD. Thank you.

Senator MITCHELL. Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman. It seems to me as I have thought over what you have said and what the panel has said that what we have tried to do in Federal health care programs is to move away from an institutional bias toward providing home and community based services. Isn't that really what we are trying to do here? In other words, take care of the elderly—by removing the emphasis on hospital and nursing home care—and indeed this proposal of Secretary Bowen has an institutional bias—and putting the accent on community-based or the home-based services. Is that the problem, the challenge that we have before us—one of the major ones?

Dr. BRODY. Yes.

Senator CHAFEE. Now, with that comes the challenge of what to do about the costs of this because, while it makes so much sense—it seems to me—and we have had a lot of testimony here about moving the people out of the hospitals into the homes and caring for them there—as your testimony, Ms. Jaycox, said about the home care—we have the difficulty of millions of individuals who are caring for their own with no Federal assistance. And suddenly, that large group will become eligible for Federal assistance under the program we are discussing. And therefore, the cost of this would be extremely high.

Have you got some thoughts on that, Dr. Brody?

Dr. Brody. Yes. I think, Senator, we have done research so many times that it gets worrisome. We have demonstrated over and over again that if you provide formal services to families, that you don't get the kind of result that you are suggesting, that families indeed don't take advantage of. And as a matter of fact, one of the big problems that we have—and I am talking clinically now—is getting older women to accept home health care into the home. This whole idea of a family just standing there waiting to be let free of responsibility just doesn't stand up——

Senator Chafee. I am not saying free of the physical responsibility. I was thinking that they might—and I am asking you—move on and take advantage of the fiscal payments that are there; but you say that doesn't happen?

Dr. Brody. It doesn't happen, not on the scale that you are talking about.

Senator Chafee. So, that isn't a concern we have to have?

Dr. Brody. I don't think so, and I will be glad to share with you whatever research is available on this. There is a fair amount.

Senator Chafee. As I understand it, what you have done in your work is to put the accent on the physical care of the individuals—rehabilitation, if you would. It seems to me, as we move into this era where the elderly are going to live much longer—which we are all excited about and hopeful about—the objective has to be that their lives not just be longer but be fruitful and in good health. Now, how much progress have we been making in keeping the elderly healthy?

Dr. Brody. Enormous. At this point, in order to demonstrate the effectiveness of programs, I usually come up with my Medicare cost. I think that the kinds of things that I do today as a senior citizen—although you are retiring me in one year, I am afraid——

Senator Chafee. Don't say we are retiring you.

Dr. Brody. Yes, you are. The retirement bill has limited tenured professors to 70 years. So, I have one more year to go. [Laughter]

Senator Chafee. I will have to speak to Senator Mitchell about that. [Laughter]

Dr. Brody. We don't want to get any precedent for Congress on that, do we? We might on some other—

Senator Chafee. Well, my concern on that isn't as great as it might be in a few years. [Laughter.]

But go ahead and tell me some of the things that you have done.

Dr. Brody. Let me give you an indication. In terms of people retiring from the work force—older workers—about half of older workers today, as against maybe 15 to 20 years ago, leave for reasons of health. The utilization of nursing homes has not escalated in the last five years, insofar as older people are concerned. The use of physicians, on a per capita basis, has not escalated as people have gotten older. So, what we are starting to see is that, as people indeed have gotten older—we are getting a widening of an aged society—there isn't any increase in utilization.

And the conclusion has to be, therefore, that we are looking at a much healthier older group. I just spoke in Florida yesterday, and all you had to do was walk down Collins Avenue to get convinced.

Senator CHAFEE. Is there some good research that shows the health of those who have access to programs—senior citizen centers, for example—where there is companionship? I would suspect that the results would show that that group were healthier.

Dr. BRODY. Not necessarily because, usually the fact that they are in a senior citizens' center, indicates that they may need more assistance than other folks.

Senator CHAFEE. I mean a community-based day center.

Dr. BRODY. Yes, I think that is a reasonable conclusion; but even more important, I think, is the fact that the tremendous number of increases in older people—and we are talking about a 70 percent increase in the last 10 years of people over 85—hasn't seen an increase in the use of the medical system proportionately.

Senator CHAFEE. I see. Thank you.

Senator MITCHELL. Senator Bradley?

Senator BRADLEY. Thank you, Mr. Chairman. Dr. Brody or anyone on the panel, I would like you to respond to the certainly inconsistent policy that we now have in Medicare coverage for home care. Let's take a case. Operation, broken hip, whatever; the system forces people out of the hospital. They are forced home. Medicare covers intermittent care, two or three days a week. Say the person can afford to spend a little more on health care and needs a person a third day or a fourth day. As soon as they pay for the third day or the fourth day, they become ineligible for Medicare coverage for the first two days.

So, you have a situation of the cliff, where they can get care for two days a week; but if they get it more than two days a week, they don't get any coverage under Medicare. Now, that doesn't make sense to me. What would you think of an idea of allowing daily coverage for a specific number of days after they are out of the hospital, say up to 60 to 90 days?

Ms. JAYCOX. I think that makes all kinds of sense because I think the problem now is in the interpretation of the law. It would not have to be interpreted as it is, and as you say, in a very bizarre way. I mean, what is supposed to be home-bound patients is now being interpreted as bed bound. So, if someone gets out of the bed to go out to an outhouse, then they are not eligible for home health care benefits. There are cases just as strange as that turning up.

And I think there has to be some way to rein in the regulators and to make it clear to them that there is a certain level of home health care which is quite legitimate and that there is a period after you get out of the hospital in which it is okay to be at home, if you are getting better. You don't have to be in an institution.

Senator BRADLEY. Dr. Brody?

Dr. BRODY. Yes. With the particular instance that you raise—the fractured hip—we have done a lot of work on that. Unfortunately, older ladies—we call it the "old ladies disease"—when they go home, they really can't get home health care because they don't need it from a medically related point of view. What they need is social support in the home because the work, in terms of hips and so forth, is done so well. But leaving that aside, I think your point has great merit. The basic issue really is that we have to disorient home health care from medical needs. I think that is the critical issue.

On top of that, there is no reason why people can't share in the cost over and above what the Government provides.

Senator **BRADLEY**. So, would you agree that we should aim as a goal up to a certain number of days of daily care rather than being locked into this intermittent care? Did you say yes?

Ms. **JAYCOX**. Yes, absolutely.

Dr. **BRODY**. Yes.

Senator **BRADLEY**. It looks as if everyone is nodding; so, for the record, they all say yes. Now, Ms. Jaycox, you made the point about the definition of homebound. We need a clarification of that definition.

Ms. **JAYCOX**. Right.

Senator **BRADLEY**. So, homebound actually means they are in their home but not that they can't get out of bed?

Ms. **JAYCOX**. No, and that they can't go out for physical therapy if they need to.

Senator **BRADLEY**. For example, if you take—and I only want to come back to this because of recent experience—a broken hip, when a person goes home, the doctor tells them you have to get up; you have to start walking on a walker. If you stay in bed, you will get the problem of bedsores; you will get the problem of this, that, and the other thing, and it complicates the medical condition. So, do you want a clear definition of homebound so that it implies some level of activity?

Ms. **JAYCOX**. Correct.

Senator **BRADLEY**. Now, what do we do about the question of quality? You know, the bureaucrats always raise the flag; any time we talk about home health care, we don't want a lot of quacks out there who are coming into people's homes, et cetera. What could you suggest in the way of monitoring quality?

Ms. **JAYCOX**. It is possible, of course, for a doctor to prescribe some kinds of assistance for an individual in need that don't necessarily have to be medically related. And because the prescription came from the doctor, you would assume that some kind of quality controls would be in place. And that would be one approach to take—to have someone who is licensed make a judgment about quality; he would be able to do that.

Senator **BRADLEY**. The yellow light is on, so let me just ask a quick question that you can answer for the next five minutes. The Medicaid option. Do you support a State option for home and community care services? You know, the current waiver is just full of so much red tape that it is unbelievable; and States end up fighting here in Washington to try to get some kind of waiver for a particular circumstance in the State. Wouldn't it be better to just give the State the option?

Ms. **JAYCOX**. Yes, and have all home health care covered and not have to go for the waiver. The Older Women's League supports that.

Dr. **BRODY**. Senator, I just want to remind you that there is a bill in the New Jersey legislature right now which would provide a very good quality control by using case management through one of the State agencies as a control mechanism.

Senator Bradley. You would support the State option?

Ms. Jaycox. Yes.

Dr. Brody. Oh, absolutely.

Mr. Clayman. Yes. Our testimony suggests the 60 days that you have indicated, plus on recommendation and certification by the physician that it may go longer.

Senator Bradley. Thank you very much for your testimony.

Ms. Blood. I was just going to say that the red light interrupted——

Senator Bradley. No, Senator Mitchell interrupted. [Laughter.]

Ms. Blood. When Senator Mitchell, I was going to say the AARP proposes that there be that State option.

Senator Bradley. Thank you very much. That is a bill that I put in last year; so I appreciate your support. [Laughter.]

Senator Mitchell. Thank you, Senator Bradley, and thank you, ladies and gentlemen, for your testimony.

The next panel consists of Trish Riley, Gail Wilensky, and Lynn Etheredge. Thank you very much for being here this morning. I am particularly pleased to welcome Trish Riley, who is the Director of the Bureau of Medical Services in the Maine Department of Human Services in Augusta, Maine, and a friend of many years and a respected professional in this field. I want to apologize to the three of you; Senator Chafee had to leave to go to the Conference on the Highway Bill and must leave to attend at least a part of that meeting.

Senator Packwood will chair the meeting in my absence. I have already reviewed some of your testimony, and will review the remainder of it. Thank you very much for your participation.

Senator Packwood. Go right ahead, Ms. Riley.

STATEMENT OF TRISH RILEY, DIRECTOR, BUREAU OF MEDICAL SERVICES, MAINE DEPARTMENT OF HUMAN SERVICES, AUGUSTA, ME

Ms. Riley. Thank you. As I guess the token bureaucrat here, I want to reassure the committee that States are doing creative programming; and I think with your help through hearings like this, we can do far more.

Maine and many other States have been able to overcome institutional bias and severe financial restraints to coordinate the fragments of existing limited programs, add State resources, and design effective community care programs.

In Maine we have built a system which serves not only the elderly, but also the physically and mentally handicapped and children; and I think they deserve your attention, too. Maine has rooted our system in client specific case management programs funded from a variety of State and Federal sources and uses a single functional assessment instrument to measure ability and disability levels for those seeking admission to any element of our long-term care system, from congregate housing to nursing homes. In this way, we will have rough indicators of the severity of need, can target those in greatest need, and will provide comparative data about clients at every level of care. Out State-funded home-based care program serves elderly, handicapped adults under the age of 60, and adult protective service clients, without regard to income.

It is funding of last resort, available only when other resources are unavailable, including both formal programs and informal care provided by families. So, there is an assurance that we don't supplant family support.

It provides gap-filling services such as homemaker, chore, adult day care, and respite care. The biggest single element of service continues to be the personal care assistant, who can be a neighbor or a trained aide. The program pays for family care, for rent, for supplies, and other needed assistance and is administered by three separate State agencies through three separate case management systems at the local level. Those are the constraints of funding sources under which we work, but it does work and it can be coordinated.

Case managers do succeed in coordinating a wide array of services to create workable plans of home care at equal to or less than the cost of nursing home care. Financed by, for example, the Older Americans Act, Social Services Block Grant, food stamps, SSI, Medicaid, Medicare, veterans' benefits, private insurance, and local funds, these programs provide a broad but limited array of services.

The job of the case manager to coordinate such a system evokes the irony that there is a single funding stream, a $30 billion expenditure, which provides every needed service as long as the roof under which one lives is not one's own home, but is a nursing home. Maine now operates three 2176 Medicaid waivers for the mentally retarded, elderly, and physically disabled through the same case management system as our home-based care program. While the waivers provide considerable State flexibility and increased income eligibility for clients, they also are difficult to administer.

Those difficulties could certainly be reduced if the program were made an optional service under Medicaid.

Optional programs under Medicaid are attractive to States in that the process of amending State plans is far more straight-forward than a formalized waiver process and because optional programs provide States needed discretion.

Using the optional services of private duty nursing and personal care assistance, combined with routine home health services, we have created the alternative long-term care program for individuals eligible for nursing homes. While routine services under Medicaid cannot be limited, optional services can; and we therefore require that ALTC clients cannot exceed nursing home costs for their total package of services. We have made one exception to this rule, to meet the special needs of heavy care individuals remaining for long-term stays in hospitals who are not accepted by the State's nursing homes.

These individuals tend to be young, very dependent, and require care for catheters, ventilators, or other life sustaining devices or, for example, are persons with AIDS. They can be served at home under our program for 80 percent of the cost of hospital care.

As part of Maine's commitment to building a balanced long-term care system that provided quality nursing homes along with other options, Maine limited the growth of new facilities primarily through the certificate of need process.

This is a very difficult thing to do and a very unpopular move with the nursing home industry. As a result, from 1981 to 1986, Maine's investment in home care grew 165 percent. It outstripped the growth of Federal expenditures in home care during that period. And our investment in nursing homes grew by only 35 percent.

Still, we spend $105 million annually for nursing homes, compared to $18 million for all home care, of which about half funds home-based care, alternative care and waiver programs. Despite our very strong efforts to create balance and choices, primary funding sources disproportionately support nursing home care alone.

We predict a doubling of home care clients by 1991, but a stable nursing home need. States can make this very, very disastrous system work but are frustrated by the lack of support and flexibility in the programs we need to somehow find a way to pull together.

In part our frustration is wondering if, in 1965, when nursing home programs were established under Medicare and Medicaid, they were subjected to the same kind of scrutiny those of us who struggle in home care now have to confront each time we try to expand: What will it cost? Can you target? We simply ask that some of the investment and some of the risks that were taken in 1965 be taken with home care now. Thank you.

Senator PACKWOOD. Thank you. Dr. Wilensky?

[The prepared written statement of Ms. Riley follows:]

TESTIMONY OF PATRICIA A. RILEY, DIRECTOR
BUREAU OF MEDICAL SERVICES/DEPARTMENT OF HUMAN SERVICES

BEFORE

SUBCOMMITTEE ON HEALTH OF THE U.S. SENATE FINANCE COMMITTEE

FEBRUARY 24, 1987

Senator Mitchell, Members of the Subcommittee on Health:

I am Patricia A. Riley, Director of Maine's Bureau of Medical Services in our Department of Human Services. This agency is responsible for health planning, certificate of need and the Medicaid program, including long-term care financing and licensing and certification. Prior to this position, I served as the Director of the state agency on aging for eight years where we developed several innovative home care and housing programs. I am delighted to be here representing Maine's Department of Human Services and to explain some of Maine's experience in developing community options-the choice of most older people and others needing long-term care.

Too often our discussions of long-term care focus on public savings only or pit nursing homes against home care rather than recognize that there are efficiencies which can be gained if a broad array of services are equally accessible and financed. The elderly population is best characterized by its enormous growth and its diversity; it contains two and three generations, rich and poor; some receive extensive assistance from family and informal supports, others none; they present the most complex medical and social conditions, each requiring different solutions.

Yet while each diagnosis and each family's ability to cope is substantially different, public policy has not recognized that diversity and has provided, primarily, one solution to the frailities of old age--the nursing home.

What we can generalize about older people is that by 75 the majority have three or more functional impairments (vision, hearing, mobility, for example) that make it difficult to carry on the activities of daily living we take for granted (bathing, feeding...). While these impairments may be caused by one or more chronic illnesses, older people generally report themselves as well and generally receive significant help from family and friends. While they need help to maintain independence, that need varies widely and is not always best met by the nursing home.

When Medicare and Medicaid were enacted by the Congress in 1965, the medical community was largely opposed to what it saw as a move toward nationalized health care and a loss of control of care by certain professionals. Perhaps in response to those professionals, these programs established an early bias toward medical models of care and institutionalization and did not provide a range of choices to meet differing social and health needs.

The Medicare Program initially paid for in-hospital care, skilled nursing care and only 100 days of home health visits. The original Medicaid program required states to provide, among mandatory benefits, skilled nursing home care and made home care an optional program only. Since home health care was generally limited to nursing visits only, it is inappropriate to refer to it as home care and compare it to services in a nursing home since it fails to provide the same comprehensive range of services provided for in a nursing home. In a nursing home, generally from one funding source (Medicaid or Medicare), a patient receives a total range of services including room (or rent), meals, utilities personal care, health care, and socialization. The home health program generally provides only the occasional nursing visit and home health aides. While some therapies are available at home under Medicare and Medicaid, the range of services, tailored to support an individual's particular needs and circumstances,has never been available. Even recent waivers and demonstration programs do not provide the full array of support available in a nursing home.

Thus from the inception of the Medicare and Medicaid program financing incentives have been available for nursing homes. While nursing homes are not the option of choice of most long-term care clients, they were often the only choice, the only service for which financing was available.

In 1965, unfettered by today's licensing, certificate of need and cost concerns, spurrned by a reliable funding source and recognizing the needs of an aging population, nursing homes grew to the $30 Billion industry they are today. Those of us trying to build more choices for long-term care clients find this history somewhat frustrating. Whenever we discuss the need to expand community care we are stopped and asked questions such as "How will we limit or target the numbers to be served?". "Will home care really substitute for nursing home care?". "Will home care supplant family care?"

The irony of the unimpeded growth of nursing homes compared to the tortuous struggle to create home care deserves consideration. While the economics and the sophistication of health and long-term care in the 1980's are clearly different from the 1960's, we need to take some of the same risks with home care that were taken to spur the growth of nursing homes and finally provide a full array of care, including congregate and other housing options, comprehensive home care, family respite care, hospice, as well as the best possible nursing home care.

Maine and many other states have been able to overcome institutional bias and severe financial restraints to coordinate the fragments of existing programs, add state resources and design effective community care programs. In Maine we have built a system which serves not only the elderly but also the physically and mentally handicapped and children. I believe it is important to recognize that the clients of the long-term care system do include, for example, accident victims, victims of multiple sclerosis and terminal diseases and the very young who can now be kept alive by technology but will require care throughout their lives. All of these individuals share functional impairments which limit their independence and all share a need for some kind of long-term help.

Maine has rooted our home care system in client specific case management programs funded from a variety of state and Federal sources and uses a single functional assessment instrument to measure ability and disability levels for those seeking admission to any element of our long-term care system--from congregate housing to nursing homes. In this way we have rough indicators of the severity of need, can target those in greatest need and can provide comparative data about clients in every level of care. All our long-term home care programs require that individuals served must be of the same severity of impairment as those eligible for nursing homes and/or boarding homes. While we cannot predict, of those eligible for nursing homes, how many would actually have entered one, we do know that some of our most difficult clients to serve are being cared for at home. Individuals who are in hospitals in days waiting placement status for nursing home care have been refused admission to nursing homes due primarily to the heavy care and staffing required for total immobility, tube feedings, suction, oxygen or other serious problems and have been placed successfully at home.

Our state funded Home Based Care Program serves elderly, handicapped adults under age 60, and Adult Protective Service clients. It is funding of last resort, available only when other resources are unavailable, including both the formal programs funded by Medicare and Medicaid, and informal care provided by families. It provides gap filling services, unavailable from other sources, such as homemaker, chore, adult day care, and respite care. The biggest element of service continues to be the personal care assistant, who can be a neighbor certified as competent to provide care, or a trained aide, but is always supervised by the family or client. The second largest service provided is home health care which points to the short comings of Medicare and Medicaid coverage since Home Based Care can only be spent when those other resources are exhausted. In some instances, the program pays for family care and for rent, supplies and other needed assistance. The program provides services in congregate housing to supplement a limited state funded congregate housing program administered by the state unit on aging. The program is administered by three separate state agencies and, through them, three separate case management systems at the local level. Case managers are often given budgets and cannot exceed the annualized cost of nursing home care for clients. However, this restrains home care since the average nursing home cost--the average of all patients in nursing homes--becomes the cap for each home care client.

Case managers succeed in coordinating a wide array of services to create workable plans of home care at equal to or less than the cost of nursing home care. Financed by, for example, the Older Americans Act, Social Services Block Grant, food stamps, SSI, Medicaid, Medicare, Veterans' benefits, private insurance and general assistance, these programs provide a bewildering but limited array of services and income generally with separate eligibility and service standards. The job of the case manager to coordinate such a system again evokes the irony that there is a single funding stream which provides every needed service as long as the roof under which one lives is not one's own home, but is a nursing home.

Maine now operates three 2176 Medicaid waivers for the mentally retarded, elderly, and is just beginning one for the physically disabled through the same case management systems as our Home Based Care Program. While the waivers provide substantial state flexibility, they also require separate systems of reporting and eligibility and are limited in their requirement that nursing home growth must be reduced. They also require an extensive application, negotiation and reapplication process which could be avoided if the program were made an optional service under Medicaid.

Optional programs under Medicaid are attractive to states in that the process of amending state plans is more straightforward than a formalized waiver process and because optional programs provide states needed discretion to limit the eligibility for and scope of service. With the help of our Health Care Financing Administration regional office, Maine has designed a new Medicaid long-term care program which serves all Medicaid eligibles based on functional need only and not age. Using the optional services of private duty nursing and personal care assistance, combined with routine home health service, we have created the Alternative Long-Term Care Program (ALTC) for individuals eligible for intermediate care facilities or skilled nursing facilities. While routine services cannot be limited, optional services can and we therefore require that ALTC clients cannot exceed nursing home costs.

We have made one exception to this rule, to meet the special needs of heavy care individuals remaining for long-term stays in hospitals and who are not accepted by the state's nursing homes. Until we complete our work to establish hospital based swing beds and develop case mix reimbursement as an incentive for facilities to care for these individuals, home care is their only alternative to inappropriate hospital stays. These individuals tend to be young, very dependent individuals requiring care for catheters, oxygen or other life sustaining devices or, for example, victims of AIDS. The program is prior approved by the Bureau of Medical Services but is again operated through local case management systems of the area agencies on aging, Adaptive Living for the Physically Disabled, and home health and child care agencies.

As part of Maine's commitment to building a balanced long-term care system that provided quality nursing homes along with other options, a brief moratorium on new nursing home construction was instituted in 1981 followed by a more rational planning process which, instead of reacting to unplanned nursing home growth, allocated through the Legislature a limited number of new beds each year for which the Department established community priorities and sought competitive certificates of need. We also established demonstration programs in nursing homes, seeking them as providers of limited home care and adult day care. Since 80% of Maine's nursing home beds are occupied by Meicaid recipients at any given time, Medicaid pre-admission screening is an important and still underdeveloped program which was strengthened during this time period, to include home visits by case managers prior to nursing home classification.

As a result, from 1981-1986, Maine's investment in home care grew 165% and our investment in nursing homes by only 35%. Still, we spend $105M annually for ICF care compared to $18M for home care. Despite our strong efforts to create balance and choices, primary funding sources disproportionately support nursing home care alone.

In 1986 state government, with strong Federal support, funded 11,440 people in nursing and boarding homes, 169 people in congregate housing and 2,200 people in Home Based Care, ALTC and waivers. Our data, however, is imprecise since it does not include all those who received routine home health service and cannot yet provide unduplicated client counts. That is, a person who receives a homemaker, a home health nurse and a home-delivered meal will be counted three times from each service provider. Our estimates, when combining all funding sources, for all services including homemakers, suggest that 10,500 individuals received some form of home care last year. Again, all of these clients were not targeted as long-term care eligibles and all of these numbers are duplicated. We predict that we serve only about 4,000 individuals in home care each year who are nursing or boarding home eligible.

The Department of Human Services coordinates long-term care through a long-term care planning committee, operating from the Commissioner's office, which includes the Directors of the Bureaus of Medical Services, Maine's Elderly and Rehabilitation and is chaired by the Deputy Commissioner. This group has just completed a long-term care plan which, based on long-term care need methodology developed by William Weissart for the University of North Carolina, concludes that Maine will have an adequate supply of nursing and boarding home beds in 1991.

Maine currently exceeds the national average in its reliance on nursing homes. In 1985 Maine ranked 18th among the states in the number of nursing home beds per thousand aged 65 and over and only six states expend more than Maine for nursing home care under the Medicaid program. About 40% of the total Medicaid budget funds nursing home care which serves about 6% of Medicaid recipients.

Using the Weissart method we predict that Maine needs between 7,687 and 9,397 nursing and boarding home beds in 1991. Based on current occupancy we will have 11,700 of these beds in 1991 or substantially more than Weissart's method predicts we need to serve our functionally impaired population.

The same method suggests we need community-based services for about 34,000 unduplicated clients in 1991. Since our current data [redacted]) show duplicated count of clients,(10,500) and not just those targeted as long-term care eligible, our ability to predict precise numbers of new clients in need by 1991 is hindered. If we assume, based upon national research, that 25.1% of the dependent population living in the community actually received some asistance from formal programs then we can predict that 8,500 Mainers (34,000 x 25.1%) will require formal home care in 1991. Based on our unvalidated estimate of how many unduplicated clients are now served at home (approximately 4,000 annually in 1986) and projecting that growth forward to 1991, we conclude that additional home care resources are required, along with better data. One cannot stem the growth of nursing homes without developing a comprehensive system which can provide a full range of services at home.

Certainly, the system is fragmented but states like Maine have created responses that patch together a meaningful system of home care service. It is not a perfect system but if home care can be this successful in light of the barriers and rigidity and the nursing home bias in funding, imagine its potential with the help of Congress.

States are not naive to the limits of Federal funds and share the conflict of scarce resources but are prepared to target, to more carefully plan nursing home growth and to restrict costs. But this cannot be done without Federal help to expand the flexibility of Medicaid, for example, through increasing optional programs; funding a wide range of options in a variety of programs such as case management, congregate housing, respite, adult day care, social services; maximizing the state's ability to manage those programs in a coordinated fashion by making service and eligibility definitions consistent and/or flexible for state's discretion; clarifying the intent of the Medicaid and Medicare programs in its coverage of skilled care and home health care to avoid the pattern of retroactive denials of care currently plauging both skilled nursing home and home health care and to provide adequate coverage of home care; and requiring and funding mechanisms to insure high quality of care standards for all long-term care services without inappropriately professionalizing home care by eliminating the valuable and needed service of non-professional staff such as personal care assistants.

We look forward to the work of this Committee as we struggle to bring a balance in our long-term care system and afford people of all ages a choice in the services they receive.

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STATEMENT OF GAIL R. WILENSKY, PH.D., DIRECTOR, CENTER FOR HEALTH AFFAIRS, PROJECT HOPE, MILLWOOD, VA

Dr. WILENSKY. Thank you. Thank you for inviting me here to testify. I am here as an independent health analyst and, although I work for Project Hope, I am not here as a representative of Project Hope.

Long-term care, as we have already heard, is the single most significant reason that the elderly experience catastrophic expenditures. Nursing home expenditures are a large and growing component of health care: $35 billion in 1985; on a per capita basis amounting to $1,250.00 per elderly person. While it accounts for 21 percent of total health care, because of the lack of coverage, 42 percent of the elderly's out-of-pocket expenditures go for nursing home care.

Nonetheless, it is important to understand that most people who require long-term care do not experience financial catastrophe for two reasons. First, most (70 percent) long-term care is provided in the home or community, and most of this—another 70 percent—is provided totally by family and friends without payment. And second, even for those who go in nursing homes, about half of all admissions are for less than three months.

When we look at the need for long-term care, we see that about 5 percent—1.4 million persons—are now in nursing homes, and another 16 percent—or 4.5 million—are disabled but in the community. As we know, the need for long-term care for chronic disabilities increases with age; and as we also know, we are about to face a large growth in the elderly population, especially among the old old.

As a result, the need for long-term care as we currently know it, may well be only the proverbial tip of the iceberg. If we look at projections based on age-specific rates of disability, we see that in terms of those with dependencies in the community, there may be five million by the year 2000 and 10 million by the year 2040, and those in nursing homes doubling by the year 2000 and doubling again by the year 2040. As we have heard from Dr. Brody, there is some argument about whether or not these age-specific projections are likely to be accurate; but even under the most optimistic assumptions, it is clear that the increased need for long-term care will continue.

The need for formal long-term care is more difficult to predict, however, because of the changing demographic and social characteristics that we are experiencing: The baby boom generation will have fewer children to provide care for itself; there is increased mobility among the elderly; more females are joining the labor force, and the increased divorce rates may exert profound impacts in terms of traditional roles provided by children.

In terms of the services that are used, we find that each person stands a 20 or 25 percent chance of spending some time in a nursing home, and that on average the length of stay in a nursing home is quite long—456 days—but as I have mentioned, half of our admissions are in fact short—under 90 days. There are about 1.1 million of the 4.6 million elderly in the community who receive some services from a paid caregiver. Most, however, is informally given without pay.

Much of the financing is personal. Medicare and Medicaid are the major two public programs affecting long-term care. Medicare provides only limited types of coverage, only for an acute episode, and only when it includes hospitalization. Medicaid funds a large part of the institutional care. Other programs such as the VA and the Social Services Block Grant provide care as does HUD through its shelter, housing, and environment. Private financing is currently very limited, but it represents an area in which there is a substantial amount of activity and innovation; and I think we have to pay close attention to what is going on there.

Until now, we as a nation have been very uncreative in the way we have financed and provided long-term care. We are, however, currently experiencing a large amount of activity in this area. The private sector, frequently with Government encouragement, is experimenting with several innovative forms of financing and delivery. Most of these innovations seem to be targetted to a limited group of the aged population, the more economically secure; and very few doubt that Government will need to be a major payor at least for the poorest of the elderly. Nonetheless, we should not ignore what is going on for we can learn much from this arena.

The channeling demonstrating represent an exception to the pattern of targetting only to the more well-to-do among the elderly. The emphasis in channeling was on the provision of case management and a rich array of home-based services. On the positive side, we saw that there was not much substitution of formal care for informal care; but on the negative side, we saw that in fact it cost more primarily because we were unable to keep enough individuals out of nursing homes.

Home equity conversions do not seem to be very promising. Social HMOs at the moment are also not looking very promising; but as the HMO market grows for the elderly, they may look better. Probably the most widely discussed private financing strategy for providing long-term care has been long-term care insurance. To date, the policies have tended to be individual. That means that they have high premiums and face adverse selection, and have tended to have narrow coverage. However, there are ways that we can improve their marketability such as attaching them to Medicare, including them as part of HMO's, but most importantly, encouraging their marketability by having them included in the packages that are offered by employers, as we do with most of the rest of health insurance.

One true breath of fresh air that has occurred from the private sector is a policy from the Travelers. What that plan does is to target persons in their pre-elderly years with insurance to cover home care, adult day care, as well as nursing home care.

These are some of the areas we need to consider when we talk about what is going on in the private sector, again emphasizing that we understand that there are some populations which the Government will have to help, no matter how successful some of these interesting innovations are.

Thank you.

Senator PACKWOOD. Thank you. Mr. Etheredge?

[The prepared written statement of Dr. Wilensky follows:]

STATEMENT OF

GAIL R. WILENSKY

BEFORE THE SUBCOMMITTEE ON HEALTH
COMMITTEE ON FINANCE, U.S. SENATE

Mr. Chairman, thank you for inviting me to testify before the Health Subcommittee. My name is Gail Wilensky. I am the Vice President of Health Affairs at Project HOPE. I am here, however, as an independent health policy analyst and not as a representative of Project HOPE.

The purpose of my presentation is to discuss long term care, the term used to cover a wide range of medical, health related and social services for persons who, because of disability or illness, need personal assistance in caring for themselves over an extended period. Long term care can be informal (unpaid care by family and friends) or formal (paid care in the community or in institutions).

Long term care is the most significant reason that the elderly experience catastrophic expenditure. Nursing home expenditures are a large and growing component of health care, $35 billion in 1985, which on a per capita basis amounts to $1250 per elderly person. Because of limited public and private financing, its direct impact on the elderly is greater than other types of health care. Nursing homes, which account for 21 percent of the total health care expenditures for the elderly, account for 42 percent of the elderly's out of pocket expenditures. Nonetheless, most people who require long term care do not experience financial catastrophe for two reasons:

First, most (71%) of long term care is provided in the home or community and most (70%) of this is provided totally by family or friends without payment;

Second, about half of all admissions are for less than 3 months.

In the sections that follow, the current and future demographics and their complications for long term care are reviewed as are current and developing strategies for financing and delivering these services. Dr. Burton Dunlop, Senior Policy Analyst of the Center for Health Affairs, assisted in the preparation of these sections.

Need for Long Term Care

Of the approximately 28 million persons 65 and over in the U.S., roughly 5 percent, or 1.4 million persons, reside in nursing homes. Another 16 percent or 4.6 million reside in the community but are disabled. 3.7 million of these 4.6 million need assistance in carrying out at least one of the basic activities of daily living (ADL), i.e., eating, bathing, toileting, ambulating and dressing. The others need help with Instrumental Activities of Daily Living (IADL) such as cooking, cleaning, shopping, handling finances, and the like.

On the average, the need for long term care for chronic disabilities increased with age. For example, only 2.6 percent of persons 65-74 need assistance in personal care (ADL) but nearly 32% of persons 85 and over need such assistance (HCFA, 1981).

The elderly population, projected to reach 65 million by 2030, is growing rapidly, especially the old-old. (See Table 1.)

Projected growth rates by age category between 1980 and 1990 are:

AGE	GROWTH RATE
65 - 74	13.8%
75 - 84	26.6% (2 times the 65-74 growth)
85 +	20.1% (3-4 times the general population growth)

As a result, the need for LTC as we currently see it may well be only the proverbial "tip of the iceberg." On the basis of current age-specific rates of disability, numbers of elderly persons with ADL dependencies in the community over the next several decades are projected to be:

1990	4.2 million
2000	5.1 million
2040	10.2 million

Similarly, based on current age-specific rates of institutionalization, the elderly population residing in nursing homes is expected to be:

1990	1.6 million
2000	2.1 million
2040	4.4 million

Need for LTC is hardly a linear function of age, however. The single most critical factor, as intimated in the preceding discussion, is level of impairment in daily functioning.

And level of disability is not shaped primarily by the relatively early killer diseases such as cancer and heart disease (less than 2%), but by chronic conditions such as dementia, arthritis and bone fractures (75%) which tend to disable a victim over a long period of time. (See Table 2.)

Most of us are aware of the ongoing debate regarding whether or not the increased longevity among the elderly has been associated with an increase or a decrease in their health status.

There are those who assume a biologically limited average life-span and who predict for the future a shortened period of morbidity and disability as we improve our ability to postpone the onset of chronic diseases. If Fries, the major proponent of this theory, is correct, the long term care burden will not increase as much as the age structure projections suggest. If this thinking is incorrect, and the biological limit on life-span is significantly higher than currently thought and/or the average age at death increases faster than our ability to postpone or mitigate chronic conditions, the period of disability will lengthen and long-term care costs will rise accordingly.

Either way, change will be gradual and the challenge of LTC need will remain and, most likely, grow in the foreseeable future.

The need for formal long term care is even harder to predict because the level of family support available to an impaired older person is often a decisive factor in their needing and seeking formal services. The level of family support in the future will be influenced by ongoing demographic and societal changes such as:

- the baby boom generation, upon reaching elderly status, will have fewer children to provide care

- the geographic proximity of the elderly and their families continues to decrease due to:

  increased mobility of the elderly (Between 1960-1970, the interstate movement of the elderly increased by 50 percent.)

- more females are joining the labor force

- the increased divorce rates, which could exert profound impact by confusing traditional role expectations and lessening the willingness of children to assume responsibility for the care of their aged divorced parents and/or step-parents

The experience of Western European democracies whose demographic patterns precede ours by about 40 years may be a precursor for the U.S. In general, with higher proportions of elderly and older elderly, they exhibit:

- higher per capita expenditures on health care for the elderly -- with a larger proportion of the elderly population receiving formal services, especially assisted housing and home care, compared to the U.S.

Services and Sources of Funding

Although the data are sketchy, especially for care delivered in noninstitutional settings, current LTC services utilization and funding presents us with the following picture:

- each person stands a 20-25% chance of spending some time in a nursing home
- nursing home residents spend an average LOS of 456 days
- about half of the admissions are for less than 90 days
- for residents staying at least 90 days, the average LOS is 830 days
- 1.1 million of the 4.6 million disabled elderly in the community receive some services from a paid care-giver
- In 1982, formal paid care-giving comprised 15% of all helper days of care (Liu & Manton) and only 5-10% of persons receiving care received all of that care from paid providers

Care-giving informally from family and friends is the predominant mode.

- According to the 1982 LTC Survey, 2.2 million care-givers cared for 1.2 in elderly an average of 4 hours/day

- two thirds of these care-givers were under age 65

The financing of long term care is varied. There is a lot of personal financing. As already indicated, much of long term care is community based and most of that informal and unpaid. The public funding for institutional care comes primarily from Medicare and Medicaid. Medicare provides coverage for both nursing homes and home care, both only for a limited period following an acute episode which includes a hospitalization. The Medicare nursing home coverage is intended to cover only persons needing short term nursing or rehabilitative services. Medicare home health is also restricted to care relating to an acute illness, although the benefit was expanded significantly in 1980. Medicaid funds substantial amounts of long term care, especially institutional care. Almost half of Medicaid expenditures go for long term care. Nursing home residents covered by Medicaid must use also all of their own income to pay for their care except for a small allowance to meet personal needs. Other public funding includes the VA and OHDS (primarily the Social Services Block Grant and Title III of the Older Americans Act). The SSI program under the Social Security Administration also funds a substantial portion of long term care indirectly through cash grants to SSI residents who reside in domiciliary care homes. One other overlooked but important indirect funding source for care of persons in sheltered housing environments is HUD through its congregate housing subsidy program.

Private financing is currently very limited with private insurance extremely limited. However, as is discussed later, there is a substantial amount of activity currently underway regarding the private financing of long term care including long term care insurance, continuing care retirement communities, social HMOs and other financing and/or delivery strategies.

The single biggest expenditure category for long-term care is nursing homes. In 1984, $32 billion, 8.3% of total national health care expenditures, went for nursing home care. This expenditure was divided about evenly between public funding and private funding. Medicaid was the dominant public source and elderly out-of-pocket was the predominant private source.

National Expenditures (in billions)
for Nursing Home Care in 1984
by Source of Funding

PUBLIC		PRIVATE	
Medicaid	$ 13.9	Out-of-Pocket	$ 15.8
Other	1.8		0.5
	$ 15.7		$ 16.3

The $15.8 billion spent out-of-pocket by the elderly for nursing home care represents 42 percent of all of their out-of-pocket expenditures for health care. Private financing mechanisms such as insurance paid for less than 2 percent of all long-term care costs. For home care, Medicare is the dominant public funding source. In 1984, $1.9 billion or 3.1% of all Medicare expenditures went to pay for home health care. Since 1980, Medicare home health care expenditures have increased at an annual compound rate of 26 percent. Medicaid, in the same year, expended $765 million for home care or 2.3 percent of all Medicaid expenditures in 1984. (These are shown in figures 1 and 2).

Private sources pay the rest of an unknown total amount of home care expenditures. As mentioned earlier, data on home care utilization and expenditures are very sparse. From the 1982 Long-Term Care Survey, we have learned that 600,00 of the 1.1

million elderly persons who received some formal home care services in 1982 incurred out-of-pocket expenditures for that care. The median expenditure for those with any out-of-pocket expenditures was $40 per month and ten percent of this group paid out over $400 per month.

Innovations in Financing Long-Term Care

Until now, we as a nation have been rather uncreative in the ways we have financed and provided long-term care. However, as of 1987, we appear to be experiencing enormous levels of activity if not yet change in this area. The private sector, often with governmental encouragement, is experimenting with several innovative forms of financing and delivery (sometime combined). Most of these innovations, however, seem to be targeted in reality to a limited segment of the aged population, usually the more economically secure, and few doubt that government will need to be a major payor, at least for the poorest of the elderly.

Channeling

A notable recent exception to this pattern was the Channeling Demonstration sponsored by the Department of Health and Human Services in 1981. The emphasis in Channeling was on the provision of case management and a richer array of home-based services. On the positive side, valuation results suggest that substitution of formal care for informal care did not occur and that service recipients felt benefited by the program. Unfortunately, however, results also showed that total costs increased because providers were unsuccessful in targeting services to those who otherwise would have received more expensive nursing home care.

Home Equity Conversion

Home Equity Conversion Plans, including Reverse Equity Mortgages, have been proposed in the past few years as a way of helping the elderly to finance their own long-term care. A full 75 percent of elderly households own their own home and 80 percent of these own their home debt-free. Average home equity in 1984 among the elderly has been estimated at $54,700. Aggregate equity for the elderly has been estimated to be $700 billion. Despite this potential, as of 1985, fewer than 1,000 home equity conversion loans were in place nationwide. For the present time, at least, this option does not seem to represent a viable strategy for large numbers of elderly, either because the institutional mechanisms are not in place or because the elderly are reluctant to use their single largest asset for purposes of long-term care.

Social HMOs

Since 1984, DHHS has sponsored S/HMO demonstrations in four sites across the country. Covered services include all Medicare benefits plus standard long-term care and other supplemental benefits. The S/HMOs require co-pay for long-term care and impose a ceiling of $5,000 - $12,000/year on LTC benefits. Enrollment has been very slow and only one of the four sites has reached its target enrollment. S/HMOs have the potential of reaching a large target population but they are still in their very early stages of development. Even regular HMO's for the Medical population are a relatively new, albeit a quickly growing phenomenon. At the moment, the market prospects are not very encouraging but that could change with time. An independent evaluation of this demonstration program will be completed by 1990.

Continuing Care Retirement Communities

Although they vary in structure, CCRCs enter into a formal contract with residents to provide certain services or to guarantee access to certain services in exchange for an entrance fee and monthly service fees from the resident. The resident usually is assured of residence or enrollment for the remainder of his or her life. Residents typically are required to have Medicare and Medigap insurance in force. Increasingly, CCRCs are contracting with private insurance carriers to re-ensure the nursing home portion of the service contract.

As of 1986, there were an estimated 300-400 CCRCs housing 100,000 - 200,000 residents. Entrance fees range from $15,000 - $175,000 and monthly service fees range from $300 to $2,000. CCRCs are projected to house two percent of the elderly population by 1990. CCRCs have attracted almost exclusively the elderly with relatively high incomes and assets. An estimated 10-20 percent of the elderly population could afford residence in a CCRC. Some experimentation with the feasibility of a CCRC arrangement for elderly with moderate incomes is being planned but results are unlikely for at least a decade. A further limiting factor in the use of CCRCs for provision of LTC is that only some, as yet unknown, proportion of the elderly may choose to live in an age-segregated environment.

Individual Medical Account (IMA)

A further proposal which has been subject to lengthy discussion over the past two years as a way of privately financing long-term care is the Individual Medical Account (IMA) for long-term care. It would be patterned after the Individual retirement Account (IRA). Detractors have pointed out that even with full tax deduction treatment, only 15 percent of taxpayers eligible to set up an IRA did so and then only less than 10 percent made the fully allowed contribution in 1984. With the very versatile IRA around, many perceived that the IMA could not compete. Now that IRAs remain in principle, albeit with the tax incentives for IRA contributions reduced drastically, many feel that the likelihood of Congressional approval for a tax incentive strong enough to attract IMA contributions is very slim. In addition, any IMA would have to include a substantial pooled risk element in order to make coverage adequate at an affordable contributory level.

LTC Insurance

Perhaps the most widely discussed private financing scheme for providing long-term care is long-term care insurance. A growing number of insurance firms are offering such policies on at least a limited basis to select elderly markets. The total number of policies in effect is estimated at 50,000 to 300,000. Market potential has been estimated at 4-7 million. Virtually all policies to date, however, have been written as individual rather than group policies. This marketing strategy leads to at least two problems: higher premiums for consumers and adverse selection for insurers.

Moreover, coverage has tended to be both shallow and narrow. An eligibility or waiting period of 90 days to 6 months is common with a limit of 2-6 years of coverage thereafter. Virtually all are indemnity policies with fixed rates per day unadjusted for inflation. Very few policies cover any service outside of a nursing home, reinforcing, some would argue, the institutional bias that has characterized LTC financing in this country.

There are a variety of ways that the marketability of long-term care insurance could be enhanced. This includes linking long-term care insurance to Medicare as part of an optional package, integrating an optional long-term care package with the traditional care offered by HMO's converting Medicare to a voucher system with the voucher usable for either acute or long-term care insurance, and combining life and long-term insurance in order to balance different life time risks.

The easiest way to enhance the marketability of long-term care insurance and the way that is most consistent with the provision of other forms of health insurance would be to have the insured be part of an employer sponsored group policy. This would provide concentrated, large volume markets, reducing marketing and administrative costs and providing convenient payroll deduction premium payments. The worksite also would provide an ideal place to educate employees about the limits of Medicare and Medicaid coverage. The misperception that Medicare, in particular, covers long-term care is widespread and appears to be a marketing barrier for most of the financing options discussed above.

Take-up, undoubtedly, would be maximized if employers went beyond sponsorship to offer LTC insurance as a choice in a benefit cafeteria plan. Few seem likely to go this far, however, given current reluctance (in the face of substantial liabilities owing to unfunded benefits in many firms) to expand any employee health benefits.

Even when just acting as sponsor of or a linkage to a group plan, however, employers seem to have a good chance of attracting employees who are in their 50's -- young enough so that affordable premiums for adequate coverage can be set. Persons of that age are likely to have experienced long-term care needs of parents and to be past the heavy expense stages of child-rearing and educating.

One "breath of truly fresh air" from the private sector has come to our attention recently in the form of The Travelers announcement of their Long-Term Care Plan designed for their corporate clients. The plan is targeted to persons in their pre-elderly years, is employer-sponsored but employee-paid, and covers home care and adult day care as well as nursing home care. It contains a 120 day qualifying period. It is an indemnity plan, paying up to $50/day for home care and $100/day for nursing home care. the plan allows the employee to continue coverage at the same group premium after leaving the sponsoring employer. It also gives the employer the option of extending coverage to the parents of active employees and to the parents of the employee's spouse, as well as to retired employees and their spouses. The

Travelers is seeking to encourage employers to emphasize to employees the limitations of Medicare, Medicaid and acute care coverage in paying for long-term care, thereby eliciting employee enrollment in the plan at pre-elderly ages.

Of course, the popularity of this approach has yet to be tested, but it represents a bold innovation relative to the stalemate that has characterized long-term financing for the past several decades.

While employer sponsored long-term care insurance could substantially enhance the marketability of long-term care insurance, there is great uncertainty as to how much of the elderly population will be able to be reached by private sector strategies. Few doubt that a substantial role will remain for the public sector and many are distressed by the current provisions of Medicaid which require recipients to completely impoverish themselves before they are eligible for long-term care assistance. Some advocate a new government sponsored universal long-term care insurance; others, want the scope of Medicare to be broadened to include a Part C which covers basic long-term care by some combination of tax financing and premiums. Still others fear that any new expansion of Federal funding in long-term care will result in major increases in Federal expenditures. What is the right public sector approach -- universal? limited? income-related catastrophic? In part the answer will depend on one's philosophy but in large part, the answer will also depend on the findings of these strategies just now being tried.

Table 1
Actual and Projected
Growth of the Older Population: United States, 1900-2040
(Numbers in Thousands)

Year	Total Population	65 Years and Over		65 to 74 Years		75 to 84 Years		85 + Years	
	All ages	Number	Percent of Total	Number	Percent of 65+	Number	Percent of 65+	Number	Percent of 65+
1900	76,303	3,084	4.0	2,189	71.0	772	25.0	123	4.0
1920	105,711	4,933	4.7	3,464	70.2	1,259	25.5	210	4.3
1940	131,669	9,019	6.8	6,375	70.7	2,278	25.3	365	4.0
1960	179,323	16,560	9.2	10,997	66.4	4,633	28.0	929	5.6
1980	226,505	25,544	11.3	15,578	61.0	7,727	30.2	2,240	8.8
2000	267,990	35,036	13.1	17,693	50.5	12,207	34.8	5,136	14.7
2020	296,339	51,386	17.3	29,769	57.9	14,280	27.8	7,337	14.3
2040	307,952	66,643	21.6	29,168	43.8	24,529	36.8	12,946	19.4

Source: U.S. Bureau of the Census, Decennial Censuses of Population, 1900-1980 and U.S. Bureau of the Census, Current Population Reports, Series P-25, No. 922, Projections of the Population of the United States: 1982 to 2050 (Advance Report), U.S. Government Printing Office, Washington, D.C. 1982.

Table 2

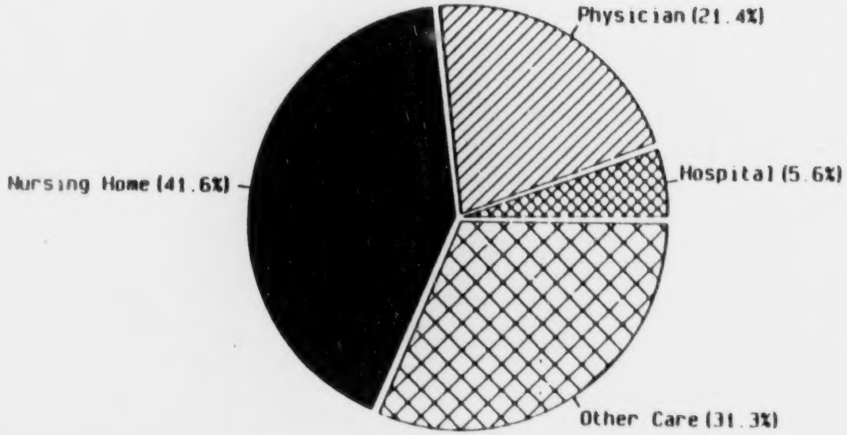
Probability of Selected Medical Conditions as the First Reported Cause of Chronic Disability among Disabled Persons, 85 Years and Older: United States, 1982

Condition	Percent
Dementia	19.43
Arthritis	16.75
Peripheral Vascular Disease	14.88
Cerebrovascular Disease	12.86
Hip & Other Fractures	8.81
Ischemic Heart Disease	1.88
Hypertension	1.38
Diabetes	1.01
Cancer	.91
Emphysema & Bronchitis	.26

SOURCE: Health Care Financing Administration, 1982 National Long-Term Care Survey

Figure 1

OUT OF POCKET HEALTH CARE EXPENDITURES
FOR THE ELDERLY
by Type of Service - 1984



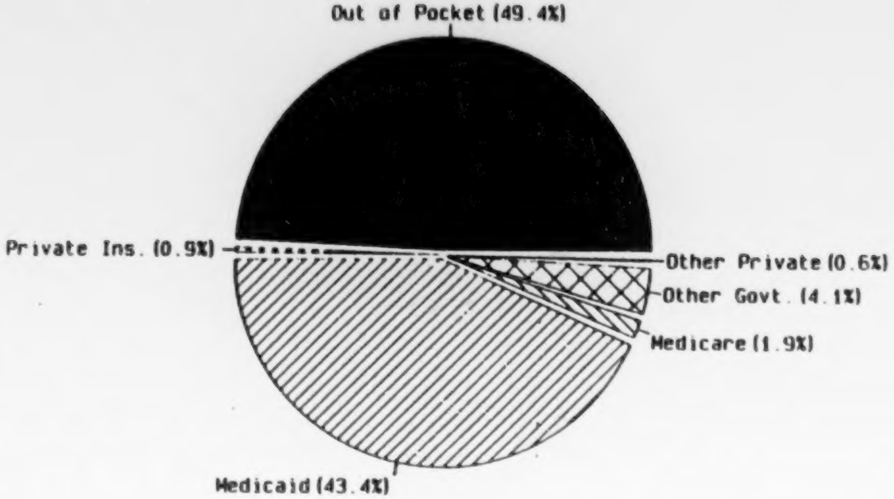
Total - $30.2 Billion

Source: Waldo and Lazenby, 1984

Figure 2

NURSING HO :PENDITURES

by Source of Payment - 1984



Total - $32 Billion

Source: Levit et al., 1985

STATEMENT OF LYNN ETHEREDGE, HEALTH POLICY CONSULTANT, CONSOLIDATED CONSULTING GROUP, WASHINGTON, DC

Mr. ETHEREDGE. Thank you, Mr. Chairman. The first panel has described three of the central problems faced by the nation's system of financing and long-term care for the elderly: inadequate insurance, underdeveloped home and community based care, and the difficulties of disabled elderly persons in putting together the financing and delivery systems.

This morning I would like to add to the discussion the results of two studies which deal primarily with solutions to these problems. One is a study sponsored by the National Governors Association of six States which are leaders in providing home and community-based care for the elderly. The States were Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin.

The second study was a review of activities, sponsored by major philanthropic foundations, to research and demonstrate financing and delivery systems of home and community-based care for the elderly.

Let me start by summarizing some of the major findings of the NGA Study concerning managing and financing home and community-based care.

First, these six States chose among three different financing strategies. One strategy was to use basic Medicaid program options. A second was Medicaid 2176 waivers. The third was to use State-only funds. In our study, we had two States that chose each of those three options.

We found the States chose depending on how they weighed the pros and cons of the different approaches. Basic Medicaid offers open-ended funding, but it is also potentially the most expensive and difficult to manage approach to financing home and community-based services. Medicaid 2176 waivers allow States even more service and income flexibility and population targetting, but they also have Federal spending limits and compliance requirements. And finally, State-only funds, which were chosen by two States as their major initiative, have a great deal of flexibility but, of course, don't have Medicaid matching.

So, none of these approaches proved to be ideal for all States and circumstances.

A second major conclusion of our study related to how States were able to pool Medicaid funds with other service programs. In brief, we found that States could use Medicaid funds very creatively and effectively. But Medicaid still requires a great deal of rules and procedures, even with 2176 waivers. States often found that expanding Medicaid meant more paperwork, billing, regulation than ever before.

As this Committee looks to the future, I think you will find States—as they develop their own management systems—which will be able to operate without many of these Federally imposed regulations.

A third area of the study was to look at whether (and how) States could achieve cost effective management of home and community-based services. We found they could if they employed a number of different methods. First, all States used three basic management tools: preadmission certification for nursing home care, patient assessments and case management.

Many States also used as management tools: limits of population eligibility, negotiated payment rates, selection of providers, cost-sharing by patients, spending limits per client, State appropriation caps, management information systems, and perhaps most importantly of all, they had good people to run the programs.

In terms of the second study, of what private foundations are doing in this area, some of these major efforts might also be of interest to the committee.

First, major studies are being undertaken of the long-term care system. These studies include the Commission on Elderly People Living Alone, headed by Dr. Robert Butler and sponsored by the Commonwealth Fund, studies by Alice Rivlin and Joshua Wiener at Brookings, which is cosponsored by five foundations, and other studies sponsored here in Washington, and at Interstudy in Minneapolis.

Among the foundation-sponsored efforts to develop home and community-based systems, the most far reaching is the Living at Home Initiative, which is sponsored by the Commonwealth Fund, the Pew Memorial Trust, Duke Endowment, Arthur Vining Davis and John A. Hartford Foundations in collaboration with 35 other foundations. This is very notable; 40 foundations have joined together to try to expand living at home possibilities for the elderly. They will be focusing on service management capacity in 20 communities. This will not be financing services; it will be financing availability of services, such as a common telephone number to call and case coordination across multiple-service agencies.

Other major initiatives in organizing services come from the Robert Wood Johnson Foundation, which is sponsoring two national programs to expand home and community-based care: one is centered on hospitals, the other on home health agencies. Together, those programs will assist 45 to 50 communities around the country.

Finally, the committee is already aware, I am sure, of the Social HMO demonstrations, which now involve 16 foundations in funding, as well as the On Lok demonstration, which has funds from three different foundations to support research and evaluation.

While this committee is considering Federal initiatives to improve long term care services this morning, both States and private sector foundations are also carrying out similar initiatives. Thank you.

Senator PACKWOOD. Thank you.

[The prepared written statement of Mr. Etheredge and answers to questions from Senator Heinz follows:]

TESTIMONY OF MR. LYNN ETHEREDGE
BEFORE THE SENATE FINANCE COMMITTEE
FEBRUARY 24, 1986

Mr. Chairman and Members of the Committee:

I appreciate the invitation to appear before you to discuss public and private financing of home and community-based long term care services for the elderly population.

My work in this area paralleled, for many years, this Committee's responsibilities for the Medicare and Medicaid programs under its jurisdiction. From 1971-1976, I served as the principal staff analyst for these two programs with the Office of Management and Budget and directed its professional health staff from 1978-1982. Much of my current consulting with private insurors, government agencies and foundations now relates to financing and delivery of long term care services.

The specific focus of my remarks this morning will be two studies about long term care services. The first study, carried out under the auspices of the National Governors Association, focused on six states which have been national leaders in developing government programs for financing home and comunity-based care services. Our purpose in that study was to see what lessons could be learned from these states' experiences which could be useful for others. The second study reviewed efforts by the nation's leading private foundations to research and demonstrate improved financing and delivery systems for home and community-based care for the elderly.[1]

Background

These state government and private foundation initiatives have started against a background of concern that the nation's long term care system, which has been strongly influenced by government policy and financing, needs some far-reaching improvements. National spending for nursing home care rose from $2 billion in 1965 to $35 billion in 1985, of which Medicaid paid the largest share. This Committee has supported a number of initiatives (such as nursing home quality assurance) to improve these current efforts, and also (through such initiatives as the Medicaid 2176 waivers, the channelling and On Lok demonstrations, and other studies) to examine the potential of home and community-based alternatives to nursing home care.

There is still substantial lack of agreement on what the nation's future long term care financing and delivery system should look like, as well as on the respective roles and responsibilities of different government and private sector actors in shaping that system. Nevertheless, I do think it is fair to say that there is widespread agreement, given the prospect of a rapidly increasing elderly population over the next half century, on the need to reexamine our long term care system and on some of the key problems involved. In brief, these problems could be summarized as:

--Inadequate insurance protection The lack of adequate insurance protection against long term care costs is one of the major gaps in our nation's public and private insurance system. In 1984, private insurance paid only 1% of national nursing home spending for the elderly and Medicare paid only 2%. Medicaid covered 42% of spending but these Medicaid benefits didn't prevent financial catastrophe; they were available only after such catastrophic expenses had forced people to exhaust most of their own resources. The elderly had to pay nearly half of all nursing home expenses out of their own pockets. The Medicaid program originally paid mostly for acute medical care, but it is now increasingly a long term care program and is not well-designed for that role. There seems no question that a much better system of public and private long term care insurance is needed.

--A lack of viable alternatives to nursing home care Partly because of the Medicaid program's emphasis on public financing for nursing home care, this part of the long term care system has grown rapidly. The growth has resulted in an extremely diverse long term care system, e.g nursing home beds per 1,000 elderly now vary more than 4:1 among states. Viable alternatives to nursing home care include a wide range of services which could enable functionally disabled people to stay in their own homes, day care centers, and various residential/service combinations which are suitable for persons with some assistance needs not requiring institutional care. It is not clear just what mix of these arrangements would be best, but many elderly persons do not now have a continuum of such service alternatives available from which they could make a choice.

--Inadequate integration of financing and delivery Individuals now in need of long term care services often face a complex process of having to qualify for several public programs, as well as arranging and paying for services. The linking of financing and delivery of long term care services so that they best serve the client, are well-managed and of high quality, and support home and community-based alternatives is a third set of problems to be addressed in the years ahead.

Study of State Initiatives in Long Term Care

The six states which are in the forefront of dealing with some of these problems and were included in our state study were Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin. These states were selected by a National Governors Association advisory council from an analysis of twelve states which were most active in developing home and community based care.[2] The final six states were selected , among other reasons, for the diversity with which these states had approached long term care reform so that a range of alternatives could be included.

The state study examined a wide range of issues about each of the programs, including history, political environment, state administrative structures, services offered, and financing. In the course of this study, approximately 30-50 key persons were interviewed per state in operating programs, administering agencies, state budget offices, governors offices, legislative fiscal committees and substantive committees, and representatives of constitutent and provider groups. My part of the study related to the financing and management of the home and community-based care initiatives. In terms of financing, for example, we were concerned with how and why states selected among different financing strategies and how well they able to integrate or "pool" funds from the Medicaid program with a variety of other sources to serve the frail elderly. In terms of management, key issues concerned what measures states had developed to assure that services were targeted to those most in need, were provided in a cost-effective manner, and managed through policy and budgetary actions.

The diversity among these six states, which was one reason for which they were chosen, makes it somewhat difficult to find valid generalizations. But perhaps that, in itself, is a valuable finding, for it indicates both that there are several successful ways to approach long term care reform issues, which is useful information for those entering this arena, and also, where we did find common ground, that some considerations and policies are now recognized as part of a core of experience which can be passed on to others.

Financing Strategies

The six states in this study chose different ways of financing their home and community-based care initiatives, but the basic choices and many issues involved in those choices were generally seen in the same way. The three funding strategies were whether to emphasize:

--the basic Medicaid authority;

--the Medicaid Section 2176 waivers; and/or

--state-only funds.

--Current Medicaid authorities The current Medicaid statute provides states with the authority to include case management, personal care services, day care, private duty nursing, and home health services in their Medicaid programs. Thus, potentially, a state could provide a very great amount of such services, with a federal match rate of 50% and more. On the other hand, states, if they offer these servcies as part of the state Medicaid plan, must meet a number of requirements, particularly providing such services, on a statewide basis, at least to the categorically eligible population. The potential costs and management difficulties of such a broad scale program, coupled with the distinct differences among Medicaid's long term care populations (e.g. developmentally disabled, chronically mentally ill, adult disabled and elderly) mitigate, for some states, against the use of these statutory authorities. Among the six states, Arkansas and Maryland emphasized Medicaid-type programs.

--The Medicaid 2176 waivers The states we studied tended to see the Medicaid 2176 waivers as having a different mix of advantages and drawbacks. The waivers allow a state to offer a very wide range of possible services beyond the normal Medicaid options (transportation, respite) and states may also somewhat increase their basic Medicaid eligibility, e.g. to 300% of normal income standards and waive some income deeming rules. Most importantly, a state may use one (or more) 2176 waivers to target different Medicaid population subgroups within a state. Thus states can use 2176 waivers to proceed, at their own pace, to develop managed systems of home and community-based care. From a state perspective, however, there are two limitations. First, states have to demonstrate, by very tightly interpreted "no additional cost" rules, that Medicaid expenses have not increased for the waivered populations. Secondly, t[illegible] reporting and compliance requirements are a fairly heavy burden. The states in the NGA study which made most use of the 2176 waiver were Oregon and Maine.

--State-only funds The third basic strategy available to states which want to expand home and community-based services for the elderly is to do so with their own funds. Such spending, for course, has the liability of not qualifying for the federal matching payments. But several states in our sample found it an attractive option for two reasons. First, this approach allows states the maximum possible flexibility to design and operate their own programs, e.g. by providing a great deal of local autonomy, or to start a program without having to immediately meet Medicaid program requirements. Secondly, this policy choice is essential for states which want, as a matter of state policy, to make home and community-based services available to individuals who do not qualify for the Medicaid program, which covers only 36% of the elderly persons with incomes below the poverty level.

States also use state-financed money for "gap-filling" of certain services not available through Medicaid or other programs. The states which made a major commitment of state-sourced funds for home and community-based care include Illinois and Wisconsin.

In sum, the current array of potential funding sources provide states with several different options for financing home and community-based care. These options can be used alone or, more frequently, in combination. They range from open-ended financing under Medicaid, with generous federal matching but the least ability to control total spending, to 2176 waivers with broader flexibility but more funding limitations and administrative requirements, to state-only funds with maximum flexibility but no federal matching.

Pooling of Medicaid and other funds

The second major financing issue which all of these states had to confront was how to "pool" funds from many different funding sources which could assist an elderly person into a viable benefit package. It is very common for a low income elderly person with disabilities to receive assistance from many funding sources, e.g. social security, SSI, food stamps, Medicaid, Medicare, social services (Title XX), and Older Americans Act, perhaps also subsidized housing, low income energy assistance, veterans benefits, and a number of other state and local programs. Each of these programs has its own eligibility and benefit rules, and a comprehensive care plan for an elderly person needs to take into account his or her needs and resources, including informal caregiving, in relation to these assistance options to put together a comprehensive plan.

One of the most interesting findings of this study, at least to me personally, were the administrative implications of "pooling" Medicaid funds, even with the Medicaid 2176 waiver programs. Medicaid funding can increase the total supply of financing and services provided, but "pooling" in not an accurate metaphor. Medicaid, even with a 2176 waiver, has exact eligibility rules. Services must be defined with standardized measures recognizable for payment by the state's Medicaid computer; similarly, rates must be established which the computer will allow, services authorized, bills filled out completely, accurately and on time. It was not unusual for local agencies which had hoped an expanded Medicaid program meant expanded autonomy and more discretionary funds, to find themselves with expanded administrative and procedural requirements, demands for standardization, regulations, paperwork, and accountability than ever before. Such administrative requirements are often not unreasonable given the Medicaid program's requirements. But states or localities which did not adequately foresee the administrative, cultural, and power-relation differences between social services financed by a block grant to a local agency and social services coordinated by a local agency but financed through a Medicaid bill-paying system often had to spend a good bit of effort on state-local negotiations.

These administrative requirements have not, of course, necessarily been undesirable for states which are venturing into home and community-based care. The Medicaid program's payment requirements can be a useful vehicle for states to establish much-needed program policies and procedures on a statewide basis and result in an ability to assure cost-effective program management and standardization of operations. But it is clear that there are still a great many strings on state fund use, and, as states gain increasing experience with managing home and community-based care, some administrative simplifications, e.g. block grant options, may prove desirable.

Cost-effective management

The NGA study also focused on measures which these six states have taken to assure that their home and community-based care programs are targeted to persons most in need and well-managed. This aspect of our findings was particularly important. We have a tendency in Washington to think health and long term care financing must be open-ended, uncontrollable spending, like Medicare was for years and Medicaid still appears to be from the U.S. Treasury perspective. In these six states, such images were not accurate

One of the most important common features of all of these programs was that they were managed systems of care. There is no doubt in my mind, nor I think with any of these program's administrators, that open-ended cost or UCR-based financing of home and community based services for the elderly would result in an explosive spending growth. Let me summarize some of the key management methods used.

To start with, while each of these states differ in some characteristics, it is telling, I think, that all of them included three basic elements:

-Pre-admission certification. Before a patient can be admitted to a nursing home at Medicaid expense, these states screen to determine if that person really needs to be in a nursing home, and if home and community-based services are a viable alternative the patient and his or her family are advised of these options. This pre-admission process helps target programs to those at imminent risk of being placed in a nursing home. In some states, this pre-admission certification may also apply to non-Medicaid patients, on grounds that nearly all nursing home admissions may lead to Medicaid spending.

-Patient assessment and care planning. In these six states, each individual receiving home and community-based care has a service plan developed, typically using standardized, quantitative assessment instruments, for the amount of home and comunity-based care which the person will need, how it will be managed and paid for.

-A case management system. The case manager is responsible for assisting clients in obtaining needed services, e.g. by providing a list of potential providers from whom a person may select, and/or making arrangements for the services. A case manager may also be responsible for seeing that services are provided within a defined budget limit.

Aside from these basic elements of a well-managed home and ommunity-based care system, the six states also made use of one and usually more) of the following program elements:

--Limited population eligibility Limiting the population which potentially eligible for home and community-based services rovides a clear upper limit on one of the most important cost- riving factors. A section 2176 waiver typically provides the most estricted coverage for a defined population group. A state rogram limited to Medicaid eligibles automatically restricts the ervice population to the categorically eligible population, with state ptions for the medically needy. State programs can define ligibility as provided by state law.

--Negotiated payment rates Persons dealing with the ledicare program are used to cost-based home health rates which un $40-60 dollars per visit. The six states in our study paid othing like this amount for most home services. A typical visit or personal care services was paid $5-7 hour, and some states ere purchasing services in some areas at near to the minimum age. Rather than escalating, like UCR payment rates, these ates seemed controllable by fee schedules or competitive urchasing. In Illinois, the state government contracts from pringfield for all services and had obtained rates which had fallen or five years in a row.

--Selected providers Another element in a well-managed rogram was typically to be selective about which providers could e allowed in the program. This involved both choosing certain ypes of providers, e.g. personal care workers rather than hospital-based home health agencies. screening for quality and negotiation of payment rates.

--Cost-sharing Patient cost-sharing has been shown to be one of the most effective ways to deal with basic health care costs and several states also make use of cost-sharing for home and community-based care services. Such an option is found in state-financed systems which expand on Medicaid's coverage, although cost-sharing can also arise in meeting Medicaid spenddown eligibility requirements. In Illinois, for example, cost-sharing is particularly important since home and community-based care is an entitlement for all elderly persons. While there seem no definitive studies of this issue, there was evidence for substantial reduction in service costs, from what otherwise would have been available on disability criteria alone, under Illinois' complex cost-sharing formula.

--Client spending limits Several of the states in the study made use of explicit client spending limits to control costs. Typically, such limits were established in setting up a plan of care, e.g. to limit spending to what would have been spent on nursing home care for a client, or to 75% of that amount. Such limits were also used in establishing local agency funding allocations and spending targets by individual case mangers for their group of clients.

--Limit state appropriation In home and community-based services, as in other government programs, an appropriation limit can be a most effective way to control spending. It may result in a queue for services and triaging of clients. Such limits also can apply to Medicaid program spending which is approximated by state legislatures. In home and community-based care, for example, an administering agency could deal with a Medicaid appropriation limit by adjusting service payment fees or the quantity of services provided to less-disabled individuals..

--Management information systems As will be apparent from the above discussion, systems which provide home and community-based care are not easily administered. They require a great deal of work to set up and run well. Moreover, these are not systems which can be left on automatic pilot. States have had to establish new management information systems for more timely and useful information than provided by the Medicaid Management Information System. Such information, for example, might include information on nursing home applications and level of impairment of those being admitted to nursing homes, results of needs assessments, determination of need scores being made by different assessment agencies and services provided in relation to those needs, costs per client, volumes and types of services being authorized, quality of care complaints and budget tracking. There also need to be quick follow-ups (e.g.SWAT teams) when problems are surfaced in some of these areas.

--Good people In the concern with technical details of how to finance and administer programs, it is sometimes too easy to overlook the critical importance of having good people to start up and run new home and community-based care programs for the elderly. Among these six states, we found all these programs were run by an exceptional group of individuals, committed both to improving services for the elderly population and to good public administration. In the final analysis, that may be the most telling common feature across all of the six states.

Private foundation initiatives

A number of the nation's major philanthropic institutions are now supporting research and demonstrations related to the nation's long term care system, including expanded home and community-based care for the elderly. It is particularly notable that several of these efforts are being supported not just by one foundation but by several foundations acting together. At the invitation of Health Affairs, I recently surveyed such foundation activities, and thought a summary of the findings might be interesting for this Committee.

The major foundation-supported studies of the nation's long term care system now include the Commission on Elderly Persons Living Alone, headed by Robert Butler and supported by the Commonwealth Fund, and a study of long term care financing by Alice Rivlin and Joshua Weiner at the Brookings Institution, which is supported by the Robert Wood Johnson, John A. Hartford, Retirement Research, Villers and Greenwall Foundations. Other major policy studies are now being supported at Lewin and Associates by the Villers Foundation and at Interstudy by the Pew Memorial Trust.

Among efforts to develop the home and community-based care system, the most far-reaching is the Living at Home Initiative which is sponsored by the Commonwealth Fund, Pew

Memorial Trust, Duke Endowment, Arthur Vining Davis and John A. Hartford Foundations in collaboration with 35 other foundations. This program will provide grants for about 20 communities to develop their service management capacity for home and community-based care, e.g. through a centralized telephone number and case management to coordinate multiple service providers. The Robert Wood Johnson Foundation sponsors two national programs, Hospital Initiatives in Long Term Care and Supportive Services Programs for Older Americans, which will assist 45-50 communities in expanding their hospital-based and home health agency-based services.

Several initiatives are also being supported by foundations to develop new capitated systems of financing and delivery of long term care services. Two of these efforts are, I am sure, already familiar to this committee. The demonstration of Social Health Maintenance Organizations (SHMO) in four sites is being supported by Robert Wood Johnson, Pew Memorial Trust, Commonwealth Fund, Henry J. Kaiser Family and Bush Foundations, along with 11 other foundations. The On Lok project, a capitated system for the frail elderly using day care centers and home services, has received support from the Robert Wood Johnson, John A. Hartford and Kaiser Family Foundations. The foundations' roles in these efforts usually complement government waivers, e.g. by supporting research and evaluation activities and technical assistance for others interested in learning more about these prototypes.

A model for private long term care insurance for the nation's colleges and universities has been developed by the Commission on College Retirement with support from the Carnegie Foundation. The model includes in-home and community-based long term care services as part of a comprehensive package and has been published for consideration by other group insurors of long term care services.[3]

Finally, there are numerous other foundation grants which relate to home and community-based services for the frail elderly. This hearing is not a forum for going into these in detail, but the topics may be of interest. The projects include individual books and policy studies, improving geriatric medical education, developing management programs for long term care services, consumer information for users of long term care, volunteer assistance programs, projects in legal assistance on issues of informed consent and guardianship, and programs for care of Alzheimer's disease patients, prevention of falls, arthritis counselling and improved prescribing practices.

I would not want to leave the Committee, by a description of these activities, with an impression that foundation funding in these areas, which is primarily targeted to the private non-profit sector, can be a substitute for government program reforms or other efforts. The funding which even a number of foundations can invest in learning and useful projects have been only a small fraction of government's long term care spending. But I think it is worth bringing to the Committee's attention that the problems and potentials of developing better systems of financing and delivery of long term care services, which are the subject of today's hearing, are ones which are now also engaging many persons in the private sector.

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[1] The state study, directed by Diane Justice, will be published by the National Governors Association later this year and was funded by the Department of Health and Human Services. The foundation study was undertaken on behalf of the policy journal Health Affairs and will also appear later this year. This testimony does not necessarily reflect the views of the National Governors Association, the Department of Health and Human Services, or Health Affairs.

[2] The states from this group which could not be included in this study were Colorado, Connecticut, Georgia, Minnesota, South Carolina, and Texas.

[3] A Plan to Create Comprehensive Group Long-Term Care Insurance For College and University Personnel Commission on College Retirement 1986

SENATOR JOHN HEINZ

Finance Committee
Hearing on Long-Term Care Policy

February 24, 1987

QUESTIONS FOR EXPERT PANEL

1. The Bowen catastrophic proposal includes tax incentives for Individual Medical Accounts to be used for nursing home care. HOW MANY PEOPLE WOULD TAKE ADVANTAGE OF THESE IF MADE AVAILABLE AND WHAT WOULD THE REVENUE LOSS BE? IS THERE ANY REASON TO EXPECT THAT PARTICIPANTS IN IMA'S WOULD BE DIFFERENT (IN TERMS OF ECONOMIC STATUS) FROM THOSE WHO PARTICIPATED IN IRA'S?

2. The Bowen proposal also includes tax incentives for purchasing private long term care coverage. TO WHAT EXTENT WOULD THIS EXPAND THE ROLE OF PRIVATE INSURANCE IN COVERING LONG TERM CARE?

3. I have introduced legislation (in the 99th Congress and intend to do so again in the 100th) to provide tax credits to families who care for their elderly parents at home. Some have raised the question of monitoring such a program to ensure that those who take the credit actually provide the care. ARE YOU AWARE OF ANY STATES THAT HAVE IMPLEMENTED SUCH A PROGRAM AND WHAT THEIR EXPERIENCE HAS BEEN? IF MONITORING IS A PROBLEM, DO YOU HAVE ANY SUGGESTIONS FOR SOLVING IT?

4. Social Health Maintenance Organizations (SHMO's) have been touted by some as the ideal solution for long term care services, since they can provide a continuum of care while controlling costs. BASED ON THE MEDICARE FINANCED SHMO PROJECTS NOW UNDERWAY, WHAT IS YOUR OPINION ABOUT THE EVENTUAL ROLE OF THIS TYPE OF PROVIDER IN MEETING THE LONG TERM CARE NEEDS OF THE ELDERLY?

5. Claude Pepper has introduced legislation to expand Medicare by adding a part C that would be financed by a new premium of approximately $600 per year. IS IT FEASIBLE TO PROVIDE LONG TERM CARE COVERAGE FOR $600 PER YEAR? (Note: Pepper's bill would require HMO or capitated programs to administer this benefit, which presumably would contain costs.)

6. GIVEN THE ACUTE CARE ORIENTATION OF THE MEDICARE PROGRAM, DO YOU SEE ANY STRUCTURAL PROBLEMS (ASSUMING THE FINANCING COULD BE WORKED OUT) TO EXPANDING MEDICARE TO COVER CHRONIC, LONG TERM CARE?

7. Home equity conversion has been cited as a valuable source of revenues to help fund long term care. WHAT HAS BEEN THE EXPERIENCE OF THE FEW HOME EQUITY CONVERSION PROGRAMS IN CHANNELING FUNDS TO LONG TERM CARE? ARE THERE PROBLEMS WITH THIS IDEA? WHY HAS IT NOT CAUGHT ON?

8. Bob Ball has suggested that long term care can be provided by increasing the payroll tax for both employers and employees by 1

percent each, if patients and their families would pick up the room costs of a nursing home (not including any of the services). ARE YOU AWARE OF ANY LONG TERM CARE INSURANCE PROGRAMS THAT DIVIDE THE SERVICES INTO ROOM COSTS VS. SERVICES? DO YOU SEE ANY PROBLEMS WITH SUCH A DIVISION?

Response to Questions from Senator John Heinz

Senate Finance Committee Hearings, February 24, 1987

Lynn Etheredge:

1. The multiplication of individual tax-advantaged retirement savings plans -- IRAs, Keoghs, pensions, life insurance, Individual Medical Accounts (IMAs) -- seems the wrong approach to improving the retirement system. No one can predict accurately, for example, what separate nursing home expenses, Medicare supplements, or income needs an individual should plan for 20 or 30 years in the future. It makes more sense for retirement planning (and simplicity) to have a single broad, tax advantaged savings vehicle, to which both an individual and employer could contribute, and then to give each person a cafeteria of options about how to use these funds at age 65.

A limited-purpose retirement vehicle, such as an IMA, would probably have less appeal to the general population than an IRA and thus be even more exclusively used by higher income persons than IRAs.

2. The major problem of developing the market in long term care insurance has been the concern of private insurors about their ability to predict and manage underwriting risks. Tax incentives for purchasers would not address this problem and are not a targetted way of stimulating the marketplace. If the Committee wants to assist the development of the private long term care insurance market, some limited reinsurance facility, e.g. with government picking up expenses over a two or three year stay, would sharply change the present risk/return calculations of many private insurors. Such a proposal would make a great deal of sense on a demonstration basis, e.g. supporting up to five plans which offered an array of benefits. Part of this arrangement should be that these demonstrations be independently evaluated and the actuarial experience thus be made available to other insurance companies. Since the government role would be reinsurance, for a limited number of demonstrations, the risks would not be large in relation to the potential of these studies to accelerate development of the private market for long term care insurance by developing the actuarial

and underwriting data needed by the insurance industry. Such demonstrations could probably be carried out without additional appropriation, through the existing Medicare and Medicaid program research, demonstration and waiver authorities.

3. (no comment)

4. There is strong reason to believe that long term care services, particularly home and community-based care, need to be managed to assure acceptable cost and quality, and the SHMO provides one way to do that. Since HMOs now enroll fewer than 2% of the elderly for basic medical care, however, the add-on provision of such services to HMOs is not now, and for the forseeable future probably will not be, a major part of the long term care system.

5. It is feasible to finance long term care services (for a representative population) for $600 per year in addition to current public financing. Assuming private long term care spending is now about $18 billion, for roughly 30 million elderly, this works out to about $600/yr, $50 per person per month.

6. The basic problem of expanding Medicare into comprehensive, chronic long term benefits is the inadequate management and delivery structure which could assure that such services, particularly home and community-based alternatives, are provided appropriately, with adequate concerns for quality and costs. Catastrophic expense limits for nursing home expenses, however, would not encounter this problem. Such limits could provide reinsurance or stop-loss protection needed to encourage private long term care insurance. This catastrophic insurance, for example, could be form of government reinsurance for the demonstrations suggested in response to a previous question (#2).

7. Home equity financing has suffered more from being a new and unaccepted idea, for both lending institutions and the elderly, than from any inherent drawbacks. Now that the tax laws have changed, my mail brings new solicitations every week from lending institutions which are starting to make this vehicle a widely accepted financing instrument. Personally, I would prefer to see home equity tapped, through estate taxes, as a way

to finance publicly-supported catastrophic insurance for long term care, but it can also make private long term care insurance much more affordable to those starting such purchases at age 65 or later.

8. I have reservations about adding still more taxes for the under 65 to pay for Medicare, particularly through use of the payroll tax, and prefer the estate tax idea as a better financing approach. As of 1984, for example, the net assets of the 65+ population exceeded $2 trillion (see Household Wealth and Asset Ownership: 1984 Bureau of the Census P-70, No.7), and a relatively modest tax on the passage of those inheritances to the next generation would provide a substantial amount of revenue, which did not fall on work income or on capital assets. But Bob Ball's idea of splitting living expenses and service payments seems eminently sensible. Indemnity payments (in effect) do this by not paying the full nursing home costs, and SSI cash benefits are also reduced for institutionalized persons. Medicare long term care benefits, for example, would thus not have to cover the full

costs of nursing home care. A recent proposal of the Harvard Medicare Project, for example, would tie the individual's copayment for nursing home care to his or her social security benefits, i.e. the "residential copayment" would be 80% of the social security benefit for an individual or, for an elderly person with a surviving spouse, 80% of the difference between the individual's and couple's benefits. Such copayments could also be made part of the reinsurance demonstrations suggested earlier, i.e. the government back-up protection could still involve some copayment liability by nursing home residents for their living expenses, to the extent these were readily financed from social security benefits.

Senator **Packwood**. Dr. Wilensky, you touched upon private insurance, and you were just starting to mention some of the options or perhaps incentives that would make it worthwhile for insurance companies to go into long-term care insurance at a cost that the average citizen could afford. Can you expand on that?

Dr. **Wilensky**. Yes. Thank you. Having spent time working with the department on the catastrophic illness project that they recently completed as part of the report for the President, I had an opportunity to read through enormous volumes of material on the provision of long-term care and perhaps trying to cover it. And it is a very discouraging exercise to be honest; at least, I personally found it discouraging as to how to get a hold of what we all recognize as a big problem, but particularly in the face of impending difficulties in funding Medicare down the road, as it is, the notion of this next large area of activity that we all agree needs to be considered.

The area that was most promising in terms of long-term care insurance was to have it be regarded as part of the employee package, an employer-provided package to the employee. And the reason is that, even when you looked at estimates of what would happen with the IMAs, if they would be adopted and given the recent tax legislation that is very unlikely, the individual medical account—excuse me, the use of a tax credit for the purchase of long-term insurance which was a different strategy that was discussed seems very unlikely because the numbers would be expected to be far less than the IRAs attracted, because it is a much more limited purpose. So, when you see that, it is very discouraging unless we can find a way to have it included in the employer package.

The area that has seemed to be most promising is to have it directed as part of the set of benefits that are offered to employees primarily in their late forties and early fifties and——

Senator **Packwood**. I am curious about that. They would be benefits that would be residual after they retire?

Dr. **Wilensky**. Well, they would continue, but they would be started—and this Traveler's package which just happened to come across my desk as an announcement—was very much the personification of the policy idea. It would be offered as part of an employee benefit package, starting—it could start any time, but I think realistically, we could only expect it to be attractive for employees who are around age 50, to be either for themselves or for their spouses or, conceivably, for their parents. And that is why the age 50 becomes important.

First, they have frequently finished putting their children through college, and as importantly, if their parents are alive, they are beginning to understand their financial potential of long-term care in a way they haven't before that.

What can be done is—if cafeteria plans are permitted to exist—that one of the many benefits that an employer would provide his employee, and it would be presumably done in trade-off—and I am not assuming it would be an addition—is to have a long-term care policy offered to the individual either for their own use or for parents or spouses.

Senator PACKWOOD. But I want to understand how it works. You are 50. Your employer has a cafeteria plan and offers the policy.

Dr. WILENSKY. Correct.

Senator PACKWOOD. And your employer may match it—it depends on how they run their program.

Dr. WILENSKY. Exactly.

Senator PACKWOOD. And you retire at 65 and you haven't used it yet. This benefit continues after you retire.

Dr. WILENSKY. It would continue in the same way that the health insurance continues after you retire for most employees. That is, it could continue, or it may not continue up to the choice of the employer and the employee. Many employers continue their health insurance to their employees as a wrap-around Medicare after the employee retires.

Senator PACKWOOD. I am curious. I was unaware that lots of employers do that.

Dr. WILENSKY. A substantial number do.

Senator PACKWOOD. Do they?

Dr. WILENSKY. Yes. Now, what they don't do and what is becoming an isse is that they frequently don't fund them, so they are not prefunded. And second, it is unclear as to whether or not they are legally liable to continue this as the LTV case, if in fact they have financial difficulty. But many employers—I think about a third of the Medigap policies—are employment related.

So, it is not predominant, but it is——

Senator PACKWOOD. But the Medigap is pretty much limited to a hospital difference; they are not for long-care difference?

Dr. WILENSKY. Yes. This area is a very new one, but at last count, at least 25, or at least in the last year or two, there have been traditionally a few plans around. They tended to be very shallow coverage—50 or 60 days for nursing home care only, and offered only on an individual basis. The problem is that they are very expensive; high marketing costs, selection problems, usually only appearing to the over-65 if not the over-70 and over-75.

There are some 25 companies now offering long-term care insurance. They have tended to begin to be a little more creative. The Travelers was so appealing because it offered coverage both for community-based care and for institutional care; and they made it as a direct part of their marketing technique to go after the employer-based part of their group business so that you lower the marketing costs and the sales costs.

Senator PACKWOOD. Presuming that the employer would offer these as a voluntary benefit, there are a number of people who would take them, you feel?

Dr. WILENSKY. Yes.

Senator PACKWOOD. Why? How do you draw that conclusion?

Dr. WILENSKY. I think that it is a way to lower the cost; that is the first thing. I agree with the comments that were made earlier that one important role the Federal Government could take would be to have a serious educational campaign. I think we have all heard the statistics that something like 50 or 60 or 70 percent of the Medicare recipients think that Medicare covers long-term care, and a large part of things that the Medigap policy covers if their Medicare doesn't. So, one part would be a very serious campaign of saying: Whatever you think, in fact, except under limited circumstances, Medicare does not; you are at risk.

Now, I assume the reason the Federal Government has not been inclined to do that is that the next obvious step would be: If you don't, why don't you? If there was something to turn to that says employers now and private insurance companies now have these wide varieties of packages available, maybe we could have a little bit more. It would take some serious education.

Senator PACKWOOD. I want to get the comments from the other two on this first, and then I have another question to follow up. Ms. Riley?

Ms. RILEY. It seems to me that there are a couple of problems. One is what the long-term care insurance covers; and I think the point is well taken that frequently it only covers nursing home care. And that is understandable in that insurance companies have historically been nervous about what the insuring event is and are worried about how to cover home care because it is so fragmented a system.

I think there is a market readily available among employees. I completely agree, that the market exists particularly among those in their middle ages who now suffer through trying to make appropriate plans of care for their own parents. And those are also the people whom we see more and more of, who are shocked by the kinds of problems their parents are having. And I think they are ripe for reasonable long-term care policies that provide for a range of services.

Senator PACKWOOD. Mr. Etheredge?

Mr. ETHEREDGE. I don't think that a stand-alone nursing home policy is the best product for this market. We don't know, or I wouldn't know what a nursing home would expect 20 or 30 years in the future, with longevity or with Alzheimer's or anything else. The kind of product that makes most sense to me is something with a sort of cafeteria of options, when one reaches age 65 or retirement. In other words, an employer could put aside so much of a pool of money in a defined contribution plan with tax advantage. Then, at age 65, the employee then knows what his economic circumstances are; and can decide how much to take as a lump-sum annuity, as an annual pension, as a Medigap supplement, or as a nursing home supplement. So, they would have that variety of options.

And I think that in terms of retirement planning is the kind of policy that would make most sense to me and make the best public——

Senator PACKWOOD. But the employee would have the option at age 65 not to go forward with it if they wanted?

Mr. ETHEREDGE. That is correct.

Senator PACKWOOD. He could cash it out, in essence?

Mr. ETHEREDGE. Or they could take it as a pension. There would be a certain lump of money there for total retirement benefits of that employee.

Senator PACKWOOD. And you are reasonably convinced that most people at 65 would opt to leave enough of it in the plan to take care of whatever they thought might be their long-term expenses?

Mr. ETHEREDGE. Oh, yes. I think so.

Senator PACKWOOD. Do you?

Mr. ETHEREDGE. Yes.

Senator PACKWOOD. What do you think, Doctor?

Dr. WILENSKY. I think that most people at age 65 are pretty uneasy about providing for their financial care—their own financial care. I think that they would be pretty cautious. I don't know what will happen with the HMO movement among the elderly. That is the other kind of option, other than our normal insurance package. That has great potential.

Right now, the demonstrations are having their fair share of troubles, as demonstrations frequently do, and the HMO movement itself among the elderly is still quite fledgling; only about a million of the 28 million beneficiaries have joined the HMOs. If that grows, the advantage to that particular type of strategy is that you will have more case management by definition because the HMO is already managing the care of the individual.

I think the only problem with the plan that Lynn Etheredge has mentioned—and I am not sure that it is necessarily a great problem at age 65—is the potential for adverse selection of making the decision then. But at age 65, people are still very healthy, and the likelihood of going into a nursing home at 65 is very low; and therefore, the probability of having an adverse selection occur, I think, is quite small. So, I think anything that increases the amount of flexibility might make it more attractive for individuals in their 50s to set aside money; but I think that people in their 50s are really beginning to understand, because of their parents' living longer, that there is a very big financial threat. And Medicaid, while it serves for some as a potential coverage if you are going to be completely impoverished, it is such an inhuman way to financially care for individuals that I think individuals, if they were given a reasonable strategy, would opt for it.

Senator PACKWOOD. Ms. Riley? Would they opt for it at 65?

Ms. RILEY. I think they would. When you think about the numbers of people who are covered by Medigap coverage and the kinds of savings that older people have many may be able to afford a policy of it marked resumable coverage. When we talk to our banking friends, they tell us that the bulk of their savings accounts are older people. And certainly, I would concur that the vast majority of people in long-term care systems are in their very late 70s and 80s when they first appear. So, I think that it is a long period of time before they would actually use the benefits.

Senator PACKWOOD. Thank you. I have no more questions. I appreciate your patience. Now, let's conclude with a panel of Val Halamandaris, Sheldon Goldberg, Paul Willging, and George Halvorson. We will take you in the order that you appear on the witness list, and we will take Mr. Halamandaris first.

STATEMENT OF VAL J. HALAMANDARIS, PRESIDENT, NATIONAL ASSOCIATION FOR HOME CARE, WASHINGTON, DC

Mr. HALAMANDARIS. Thank you, Senator Packwood. It is a pleasure to be with you here today. I would like to commend you for your leadership, as always. For years, the American public said we would never get a tax reform bill. Thanks to you and your leadership and this committee, we have one. For all the years that I sat downstairs as the Chief Counsel for the Senate Aging Committee, they said we would never have a long-term care bill. Why do I think that you are going to be a key player in the solution of that great dilemma?

I know you have a lot of support in Senator Mitchell, Senator Bentsen, Senator Bradley, and this committee, and I somehow feel in my bones that this is going to be the year that we solve the great problem that we have had in long-term care.

I am very happy to be representing the visiting nurses' associations and the home health agencies of the country. Home care is a very proud tradition. A hundred years ago, we were faced with a major crisis. The crisis was that we had epidemics racing across the land, and we had immigrants in this country who couldn't be expected to understand our language, who could not be expected to understand Western medicine. We needed some mechanism of bringing health care to the people in their own homes. Home health care then was created as the solution.

Today, I am suggesting that the same circumstances which existed 100 years ago are present. We have a raging epidemic, perhaps the worst epidemic in the history of mankind in the form of AIDS across the country to deal with. We also have the greatest influx of immigrants that we have had since 100 years ago. We also have another problem in the form of increased longevity for senior citizens.

We have been given a gift, Mr. Chairman, a gift of the third age. We are living an average of 30 years longer than we did at the turn of the century. Part of the problem with that gift is that, as we have set back mortality, there has been a concomitant increase in morbidity. Now, the question is how do we resolve this problem?

I would suggest to you that home care must be at the center of any solution of the problem of long-term care.

Now, exactly what is long-term care? Some people think long-term care is synonymous with nursing home care. I would like to suggest to you that it is far broader than that.

Secondly, it is not limited to the elderly. Long-time care has much more to do with functional disability than anything else. It has to do with impairments--impairments that come about as a result of birth, birth defects; impairments that come about as a result of disease; impairments that are related to injury and through the inexorable process of aging. All these mean that we have disabilities and impairments and therefore must turn increasingly to others for our help and our protection.

Now, the question is: How do we meet the basic needs of these people who need help? And what I would suggest is that we look to other societies and see what they have done.

The British, in my judgment, have the best and most comprehensive system of long-term care. It is not simply my saying that; rather, this was the conclusion of the Senate Aging Committee in a report we issued several years ago.

Now, there are several basic principles that the British use. First of all, they make available the broad spectrum of services, so services can be increasingly tailored to the needs of each specific individual. These services include hospital care, nursing home care, day care, respite care, and home health care, physician's services set and telephone reassurance, so that you can tailor the care to specific needs.

Secondly, they have strong incentives to encourage families to provide long-term care for their relatives.

Thirdly, they make maximum use of the least expensive services. Fourth, they try to do as much as possible for people in their own homes. And fifth, considerable effort or attention is placed on efforts to rehabilitate those people who are in need. If you can rehabilitate people and keep them out of the expensive hospital bed or the nursing home bed, the program benefits and also families and individuals benefit.

Now, one question a lot of people ask me is: Is home care really a viable option for the most acute and the most serious patients, the ones that we find in nursing homes today? And I would suggest the answer is yes, even in the most acute. There is no patient, I would offer, Mr. Chairman, that is harder to handle than a very fragile infant, an infant who is dependent on the ventilator 24 hours a day for literally every breath. Those infants now are being managed at home, which is to say that home health care is doing what hospitals used to do, much less what is done in nursing homes.

I would pose to you that even the most serious and the most acute cases—senior citizens with multiple disabilities—can and are being taken care of at home. I would suggest also, Mr. Chairman, that there are several programs in the country that this committee should consider very carefully.

If you are asking me to name the best of these, I would suggest the Nursing Home Without Walls program in New York. The Nursing Home Without Walls program is an effort to keep people out of hospitals and out of long-term care facilities. The program has saved the State of New York over 50 percent of what they now spend or would ordinarily have spent to put people into long-term care facilities; and that program is described in detail in my testimony.

The second program, which is based on the British system, is outlined in my testimony; and it is called the Minneapolis Age and Opportunity Center.

One final comment about the so-called woodworking effect. So many people say that we can't afford to provide home care because it is too good. If we make it available, people will come out of the woodwork and use it. It will supplant care which is offered by families and relatives. I suggest to you, Mr. Chairman, that that argument has a hollow ring when we are talking about the one million people that the General Accounting Office has said at the present time have nobody to care for them, no one at all. The argument also doesn't apply to those people who are on the runway for admission to a long-term care facility.

We have to address the needs of these people first, and then expand that. Hopefully, Mr. Chairman, this committee will come to some agreement, some solution to this problem.

Senator MITCHELL. Thank you very much, Mr. Halamandaris. Mr. Goldberg?

[The prepared written statement of Mr. Halamandaris follows:]

Testimony of Val J. Halamandaris, President
National Association for Home Care
Before the Subcommittee on Health
U. S. Senate Finance Committee

Mr. Chairman and Members of the Committee:

It is a pleasure to be with you this morning as you examine the important subject of long-term care. I am here representing the National Association for Home Care, an organization of some 5,000 home health agencies, homemaker-home health aide organizations and hospices. I would like to commend you for calling this hearing and to thank you for an opportunity to appear before you.

Mr. Chairman, home health care is a proud tradition. Some 100 years ago the Visiting Nurse Associations were formed in response to a growing national crisis. One epidemic after another was racing across the land. There was at that time a tremendous influx of immigrants--immigrants who could not speak our language and who could not be relied upon to seek out western medical care. There was a strong need to bring health care to the people in their own homes--no matter how humble that home might have been.

The VNAs responded to the crisis. Nurses, therapists, aides and volunteers teamed together to educate the public and to bring home to them the basic rudiments of modern health care. They provided care for expectant mothers, for young children, for the disabled and the elderly.

Today, we face conditions which are strikingly similar. In AIDS, we have the worst epidemic in the history of mankind to fight. We have at the same time the largest migrations of immigrants that we have had at anytime since 100 years ago. To make matters even more complicated, modern science has helped us extend life, giving us the gift of thousands of infants who previously would have died and extending the lives of millions of elderly. The price of the gift in both cases is the continuing need for long-term care. The health care challenges facing us are greater now, therefore, than ever before.

The home care agencies of today, like their predecessors of 100 years ago, stand ready to meet this challenge. Now as before, our thousands of nurses, physicians, therapists and aides are providing both short and long-term care to that group of Americans former Vice President Hubert H. Humphrey described as being on the fringes of life. With your help, we will do more and more in the years to come.

BACKGROUND: WHAT'S PAST IS PROLOGUE

As you may know, the subject of long-term care is close to my heart. I began my career working with U. S. Senator Frank E. Moss 25 years ago when he helped found the Senate Special Committee on Aging and became chairman in 1962 of it Subcommittee on Long-Term Care. I worked with the Senator and with the Senate Committee for 15 years; health care of the elderly and long-term care were my areas of specialization. I spent five additional years as Counsel to Congressman Claude Pepper's House Select Committee on Aging.

After 20 years with the Congress, I moved to the National Association for Home Care because I could see that long-term care was going to one of the major health dilemmas for the balance of the 20th Century and because I believed that home care offered the best hope for a solution to the problem.

Senator Moss and I learned about home care in the course of an investigation into nursing home abuses. One series of hearings began in 1962 and ended in 1965. Another began in 1969 and in 1976, after accumulating 3,000 pages of testimony. I authored a 11 volume report called, "Nursing Home Care in the United States: Failure in Public Policy," and a 48-bill reform package carrying out the Committee's recommendations.

The major conclusion of that report is as valid today as it was 11 years ago. The report said:

> Despite heavy commitments to long-term care, a coherent national policy has yet to be developed to meet the long-term care needs of the elderly. Thousands of seniors go without the care they need. Others are in facilities inappropriate to their needs. Perhaps, most unfortunate, institutionalizations could have been postponed or prevented for thousands of current nursing home residents if viable home health and supportive services existed. Although such alternative forms of care may be more desirable from the standpoint of the elderly patient--as well as substantially less expensive--the Department of Health, Education and Welfare has given only token support of such programs.

It is noteworthy to me that long-term care has been a major issue in each of the past three White House Conferences on Aging.

The 1961 delegates resolved to ask for the development of "noninstitutional alternatives, partcularly treating the patient in his own home."

Ten years later, President Richard Nixon told the 1971 White House Conference that "the greatest need is to help older Americans to live on in their own homes."

The 1981 Conferees also spoke of the challenge of long-term care and the need to provide "alternatives to institutionalization."

To be sure, we have made progress along the way. I was proud to help Senator Moss add provisions covering home health care to the Medicare and Medicaid programs in 1965 and 1967 respectively. We have come far but we have far to go.

DEFINITIONS: WHAT DO WE MEAN BY LONG-TERM CARE?

What is long-term care? It is almost impossible to fashion any kind of meaningful national program unless we have agreement on what constitutes long-term care. Unfortunately, there is little consensus what the term means. Some people think the term is synonomous with nursing home care which it is not. Some think it only covers health care services; others that it is limited to the provision of social or supportive services.

In trying to fix a definition, many people work backwards. They try to agree on what long-term care is not. They try to define a term by looking at its opposite. Some people say that long-term care is the opposite of short-term acute care.

I suggest that the term has less to do with the locus of and length of treatment than it does with the degree of a person's functional impairment and need for assistance.

There are millions of Americans today who suffer from physical and mental problems which lead to impairment and disability. These impairments and disabilities may range from moderate to severe. In their extreme, the impairments render these persons unable to care for themselves and so they become totally dependent upon others.

What causes these impairments and disabilities? Some are congenital and are caused at birth. Others are brought by disease, injury or the inexorable process of aging. What these impairments and disabilities have in common is that they are chronic which is to say there is no cure and that they may extend for a long period of time--sometimes for the life of the individual.

The degree of impairment and disability varies greatly from person to person depending on its cause. In some individuals, impairments ebb and flow like the tide. In others, disability remains constant. In still others, it becomes progressive. It is rare but there are instances of dramatic recovery or remission in some so-called chronic conditions.

The disabilities and impairments which lead to the need for assistance in performing the tasks of daily living are not limited to the elderly. There are thousands of children and millions of disabled individuals of all ages who must be considered in the equation.

Long-term care therefore implies the need for assistance in the form of health care or supportive services to help those in need to perform the activities of daily living. Such care may be required 24 hours a day or half an hour once a month. The expectation is that such care will be needed at greater or lesser levels of intensity over the long-term.

HOW MANY PEOPLE NEED LONG-TERM CARE?

The National Center on Health Statistics estimates that there were about 5 million older Americans in 1985 who needed help performing the activities of daily living.

The U. S. General Accounting Office, in a January 1987 report cites 1982 data to the effect that 5.2 million elderly people need regular home nursing or other assistance to remain in their own homes. GAO said that 1.9 million of them were receiving home care mostly (71 percent) through relatives. GAO also said that 1.1 million Americans were going without the care they need. Many of these have no family and no means to pay for home care services.

The Congressional Budget Office estimated that 5 to 10 million adults needed long-term care services in 1975. In that year CBO estimated there would be 7.4 to 11.5 millions disabled adults in need of long-term care in 1985.

None of the above figures includes infants born with birth defects or children who are victims of accidents. One study by Vanderbilt University places the number of these individuals at 10 million. Fortunately, many of the children outgrow their dependence and the need for long-term care. In others, the need is life long.

Obviously, the problem is enormous in scope. The problem will also increase by geometric proportions as time goes by.

WHAT ARE SOME COMMON EXAMPLES OF PEOPLE WHO NEED LONG-TERM CARE?

Following are some common examples of individuals who need long-term care:

* A senior citizen or young child with diabetes whose diet, sugar level and intake of insulin must be managed very carefully. There is no cure for this disease which in its severe forms leads to blindness, heart disease and other problems.

* A person who cannot go to the toilet without help or a person who is incontinent.

* A person with bedsores (decubiti) or other wounds/burns which take a long time (if ever) to heal.

* A person who is paralyzed from a stroke and undertaking a course of rehabilitation (assuming rehabilitation is possible.)

* A person with a broken hip or a total hip replacement. While the surgery and repair can be done in the hospital, it takes weeks or months for senior citizens in particular to recover and gather strength following such episodes.

* A person who has lost one or more limbs.

* A person with Alzheimer's disease.

* A person who is blind whether or not complicated by other health problems.

* A person with emphysema whose diminished lung capacity leaves them out of breath, susceptible to infections and causes severe pressure on the heart.

* A person prone to congestive heart failure whose salt intake and fluid levels have to be monitored carefully.

* A person taking several different kinds of medications who has problems taking the proper drug in the proper amount at the proper time.

* A person who cannot eat normal food because of disease or disability and has to be fed liquids through a tube or intravenously.

* A person who is dependent on a respirator to breath for any part of the day or night.

* A person who cannot do any of the following: get out of bed, get dressed, go the the bathroom, wash, make his or her own meals, change the bed, go to the the grocery, dispense their own drugs, and undertake their own therapy without assistance.

WHAT ARE THE BASIC ELEMENTS OF A SUCCESSFUL LONG-TERM CARE PROGRAM?

The British have a fairly successful long-term care program. Their success rests on several principles.

1. They provide for a broad spectrum of services so that services can be tailored to the specific needs of the individual.

Among the services made available are hospital care, nursing home care, day care, respite care, home health care, home-delivered meals, transportation services, homemaker services, telephone reassurance, counseling, and, of course, physicians' services.

2. They include strong incentives to encourage families to provide long-term care services for relatives.

3. They make maximum use of the less expensive services and endeavor to keep the most expensive (hospital stays) services to an absolute minimum.

4. As much as possible, they try to provide care at home.

5. Considerable effort is directed at rehabilitation and/or reducing the extent of the disability. The result is that the patient is made as self-sufficient as possible, which reduces overall cost to the program.

IS HOME HEALTH CARE A VIABLE OPTION FOR LONG-TERM CARE, OR IS A NURSING HOME THE ONLY ANSWER?

The literature is replete with studies which suggest that 25 to 40 percent of the nation's nursing home residents do not need to be institutionalized. My guess is that the majority of patients could be cared for at home. In my judgment, home care must be at the center of any long-term care program.

Before Medicare came along, home health agencies were typically providing care for individuals with intensive medical and nursing needs (some requiring 24 hour around-the-clock care). The nature of the Medicare home care benefit is limited to skilled nursing care and other therapy rendered on a short-term intermittent basis. Because the Medicare statute is written that way does not mean that home health agencies are not capable of providing the intensive services which are found in a nursing home or hospital.

The recent experience with fragile and profoundly disabled youngsters is instructive. In the past two or three years, the technology which saved the lives of premature infants has been miniaturized and made portable. This fact, coupled with the increased training and sophistication of home care personnel, has made it possible to bring these infants with their intensive medical and nursing needs home. Some of these children are ventilator-dependent. They depend on a respirator for their every breath. As Surgeon General Koop has said, "If we can bring **these** children home, we can bring them all home."

I would suggest that there are few senior citizens in nursing homes, even with their multiple disabilities, who are more of a challenge to care for than are these fragile children. What's more, the cost of caring for them at home through home care is about 1/10th of the cost of a comparable hospital stay and half of the cost of a nursing home stay.

Technology has developed to the point that home health agencies are providing health care services which previously were only available in the hospital. One example is intravenous nutrition and medication. Not many people know, for example, how much IV chemotherapy is done at home as opposed to the hospital. Studies suggest that it is not only less expensive but also more efficacious. Other examples are home blood testing, home diagnosis, portable X-ray machines, and electrocardiograph units.

There is also the subject of consumer preference. Our studies conducted by Forecasting International and those of the American Association of Retired Persons indicate senior citizens and the American public in general prefer home care by a wide margin over similar long-term care in a nursing home.

Good nursing homes will always be a valuable part of our health care system. I am suggesting merely that ideally they should play a role secondary to home care.

The final answer to this question is that all of the examples that I have cited above are being cared for at the present time through home health care.

WHAT ARE THE BEST HOME CARE PROGRAMS IN THE NATION WHICH PROVIDE LONG-TERM CARE?

Many home health agencies including the VNAs now provide long-term care for patients who can pay privately. These programs are specifically tailored to meet the needs of the client and his/her family. It goes without saying that if the financing were available, home health agencies could care for most long-term care patients and usually it will be less expensive than comparable nursing home placement. It will always be less expensive than care in a hospital.

One of the best programs I know of is the Nursing Home Without Walls Program, also known as the Lombardi Plan, in New York State.

The program was conceived as a way to reduce Medicaid nursing home costs. It has a number of key features. First, certain providers are selected by the state and approved to participate. Second, a partnership is developed between the provider and the social services staff. Third, to qualify, a client must be approved for nursing home placement. The client and his family are notified of the existence of the program and may or may not elect to use it. If the family agrees, a comprehensive assessment is done jointly by the provider and the social services staff. The state, through its Department of Social Services, acts as the case manager in partnership with the provider, who is given the freedom to provide any of a broad range of services to keep the patient from being institutionalized. The range of services allowed includes: nursing, physical therapy, occupational therapy, speech pathology, medical social services, respiratory therapy, nutritional couselling, audiology, medical supplies and equipment, personal care, home health aide, homemaker, housekeeper, social day care, respite care, home-delivered meals, congregate meals, transportation, housing improvement, home maintenance, personal emergency response systems, and moving assistance.

The only restriction to the above is that the state must be satisfied on the quality of care. Health, environmental, and social reassessments are performed every 120 days after a patient is admitted to the comprehensive home care program. Second, there is a cost cap in payments to the home health agency of 75 percent of the cost of the average annual rates of payment for skilled nursing care in the state. The provider must give all care for the patient within this limitation.

Accordingly, to the State of New York, the program has been enormously successful. Reportedly, the state has concluded the program has also saved them at least 50 percent of the cost of comparable care had patients in the program been institutionalized.

The other program is, at its heart, a home health agency. It is called the Minneapolis Age and Opportunity Center, and it is located in the Twin Cities. MAO as it is called is based in large part on the British system. Its funding is a patchwork quilt of half a dozen government programs, combined with some state money and private contributions, but the results are wonderful.

Representatives from more than 60 nations have toured MAO to try to learn its secret. It is a program which tries to meet both the social and the health needs of the seniors in the Twin Cities area. MAO's leader, Daphne Krause, makes the point that the two are intertwined and it is foolish to separate them.

MAO has a staff of social workers who meet with the elderly in their own homes or at the MAO office. They assess the seniors' needs. They write what I call a "social prescription" for each individual. If, for example, the person is lonely, they put the person to work calling other lonely people in a telephone reassurance network. If the person needs legal services, they are provided in the form of legal aid lawyers, usually retired lawyers who volunteer their time. An attempt is always made to meet the person's needs through volunteers or existing community resources.

On the medical side, MAO operates a free clinic in conjunction with a local hospital. It is free in the sense that Medicare is accepted as full and complete payment. The clinic does a comprehensive examination of the patient. If the patient needs to be hospitalized, the hospital accepts whatever Medicare pays and the physicians do as well.

If the patient needs home delivered meals, transportation services, homemaker services, physical therapy, or home nursing care, all of these are provided.

Medicare pays for the home health services to a limited extent. Title XX provides some money for homemaker services. Meals are provided under the Older Americans Act nutrition program. The gaps -- and they have been growing in recent years -- are made up with private contributions.

The remarkable thing about the program is that it targets senior citizens who are about to be admitted to a long-term care facility. MAO has kept elaborate records showing that they have provided long-term care for people for two and three years, helping to keep them independent in their own homes for a fraction of the comparable stay in a Medicaid nursing home.

It is to me a great tragedy to see Medicaid contributions to nursing home care increased by billions and billions and now constituting about half of the entire program, and yet payments for home care still hover at a pathetically low level of about 1 percent of the entire program, or about $500 million. Indeed, a viable Medicaid home care program exists in my judgment in only one state, New York, and you have heard about the results earlier in my remarks.

THE WOODWORKING EFFECT

The excuse for not broadening the home care benefit in Medicare or Medicaid has always been that it is too good an idea. It has been suggested that people would come "out of the woodwork" to take advantage of the benefit if it were available and this would have the effect of supplanting care provided by families themselves.

It is very difficult to sustain this argument in the case of the 1 million individuals that GAO and CBO have identified who need care and have no one to care for them. It is especially so when such people wind up in the hospital or nursing home at many times the cost.

It is also difficult to sustain this objection with respect to those individuals who are in the process of being admitted to the nursing home.

If I were looking to provide a solution to the most acute problems that we have in long-term care, I would look hard at both of these two populations. Moreover, I would take a good look at the two programs that I mentioned.

I would look very hard at ways to reduce the Medicaid nursing home expense which represents the lion's share of that program. The Lombardi plan seems to be one answer to the question of how to use the same or less dollars and provide care for thousands of additional people.

Ultimately, long-term care is an expensive proposition. The cost of the program must be shared by the federal and state governments, by insurance and third-party payors, and by individuals themselves. In all respects, what is obvious is that home care must be at the center of any future efforts to meet the growing long-term care needs of the nation.

STATEMENT OF SHELDON GOLDBERG, EXECUTIVE VICE PRESIDENT, AMERICAN ASSOCIATION OF HOMES FOR THE AGED, WASHINGTON, DC

Mr. GOLDBERG. Mr. Chairman, I appreciate very much the opportunity to testify today before this committee. I represent the American Association of Homes for the Aged. We are nonprofit providers of care of nursing homes, of community services, of housing, of continuing care communities, life care communities as they are often referred to. Some of our members of our organization predate the Constitution of the United States by providing care and service to the elderly in this country for well over 200 years. We hope they will continue to do that well into the future.

We would like to commend first the President for his initiating the catastrophic proposals. Although we have a number of concerns with the proposal which has been surfaced and obviously sent to the Congress, I would like to just briefly elaborate on some of those concerns.

Number one, the proposal which has been made by the Administration would benefit no more than three percent of the eligible beneficiaries in the country. Number two, it fails to address what we feel is the true catastrophic loss that the elderly are most vulnerable for, and that is obviously the expenses of nursing homes and home health care and a number of other programs which support their independence and their continued existence.

The President's statement, which concerns us perhaps most intensely, refers to the last measure of security; and our biggest concern there is that this may lead the elderly to an erroneous conclusion, a conclusion that this will meet their needs, when in fact we believe it will perhaps only address the needs of about three percent of the elderly in this country. It is important to note that the elderly pay for no more than 5.6 percent of the national acute care health expenditures in this country. Obviously, that is a tremendous amount of money, but it is a minor portion of the cost in that area.

The Administration's proposal does not address a number of issues. Obviously, it does not address nursing home benefits under the Medicare program. It does not meet or even address the expansion of home health care, adult day care, and a number of other services meant to keep people independently, keep them in their own homes.

As a matter of fact, it tends to almost have conflict with the President's and the Administration's own budget proposal, which tends to scale those same programs back, which obviously keep people independent. And obviously, it does not begin to address prescriptions, drugs, vision, hearing, dental care, and a host of other services that can be catastrophic to the elderly, especially low income elderly.

It is important to note that the elderly in this country pay for 50 percent out-of-pocket for the expenses of nursing homes. We believe with the elderly in this country, the true catastrophic exposure they have is the home health care to nursing home and a host of other services.

If I can just put a very quick baseline on what is going on within this country, both in terms of the Medicare private pay, the public insurance and the Medicaid programs. The Medicare program is obviously acute care oriented; it is obviously oriented to the hospitals. In order to even begin to access the nursing home coverage, it requires a three-day prior hospitalization. You first have to go to the hospital, and it has a very, very limited benefit—usually no more than 20 to 25 days of coverage.

Home health care literally requires the person to be bedridden at home. It is not homebound; it is bedridden. And obviously, it pays for less than two percent of the nursing home expenditures in this country.

On the Medicaid side, in terms of its impact on this program, 47 percent of the expenditures for nursing homes were paid for by the Medicaid program. It is an indigent program. Perhaps one of our most deep concerns is what it does to the spouse who is left at home; it literally creates impoverishment. One statistic I recently came across was that, in the State of Indiana, the allowance for the spouse remaining in their own home is $258.00 a month. Obviously, that person is living way, way below the poverty lines within this country. And obviously, as we look at private insurance in this country, it pays for less than one percent of the expenditures on nursing home coverage—a very minimal penetration, very limited access and the exposure and development of products in the future. And one of our concerns is how it is being marketed to the elderly and the scope of coverage that really is available to the elderly in those areas.

Obviously, we have some recommendations we would like to share with this committee and yourself. Obviously, we support a public/private partnership. There is a role for the Federal Government in this, as well as State governments and local governments; but there is also a very clear role for the private sector—the insurance carriers in this country and we think the nonprofits as well.

We would like to expand upon the President's recommendations and, obviously, perhaps an incremental approach. We recognize the reality facing this Congress with deficits, and so, therefore, we can't create a national health insurance system at this point in time; but certainly, there are incremental improvements we can make to Medicare and Medicaid to help address those.

If I might start with the Bowen recommendations, specifically the IMA, very much supported—the ability for individuals to take responsibility and to put money away for their future needs and future long-term care needs.

Tax exemptions obviously for those individuals which purchase long-term care insurance policies—very much important. A 50 percent tax credit. In essence, we would support the original Bowen recommendations. Those are not supported by the Administration, but we feel those are very, very important.

If I could add to the series of Bowen recommendations, which are contained in our testimony, obviously we would like to surface a new idea. One idea is that for those individuals who do take the initiative of purchasing long-term care insurance—whether it be for two years, three years, or four years of coverage—the potential would exist where perhaps Medicaid could be expanded to assure them that they don't have to spend down their own resources, at the conclusion before they have to go into a nursing home, or utilize those home health services for two, three, or four years.

Expand the social health maintenance organization. There is much to learn. There is a lot of exposure. The Federal Government has a lot to learn from those projects, as well as private insurance carriers. Literally, a whole series of incremental adjustments.

If I can address one specific issue because I think it has the most profound effect on families in this country, and that is under the Medicaid program. We currently impoverish spouses of those who have to go into nursing homes. I indicated that in Indiana $258.00 is all that is allowed to the spouse that remains home and believes in independence.

There are a number of other issues that we would like to address, and obviously, time does not permit—such things as life care, which is probably the largest penetration of long-term care insurance in this country; and I believe those are indicated.

One last point is education. The elderly in this country are exposed to tremendous catastrophic loss. Most do not realize what they are. The leadership you show on this committee, the Administration and all involved is very important in communicating that to the elderly. Thank you very much.

Senator MITCHELL. Thank you, Mr. Goldberg. Dr. Willging?

[The prepared written statement of Mr. Goldberg follows:]

A A H A

Statement by

SHELDON GOLDBERG, EXECUTIVE VICE PRESIDENT

AMERICAN ASSOCIATION OF HOMES FOR THE AGING

on

LONG TERM CARE

before the

SUBCOMMITTEE ON HEALTH

of the

COMMITTEE ON FINANCE

UNITED STATES SENATE

Washington, D.C.

Feburary 24, 1987

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Edgar G. Kilby *President* ■ Sheldon L. Goldberg, *Executive Vice President*

Chairman Mitchell and members of the Health Subcommittee, I am Sheldon Goldberg, Executive Vice President of the American Association of Homes for the Aging (AAHA). AAHA appreciates the opportunity to testify before this Subcommittee on the pressing and critical issue of long-term care. At the outset, it must be emphasized that payment for long-term care services constitutes the true catastrophic risk of the elderly. As detailed below, inadequate coverage of long-term care services under public programs and private insurance and significant service gaps pervade this nation's fragmented "system" of long-term care. The American Association of Homes for the Aging is here today to urge you to take advantage of the unique opportunity now before the Congress by expanding the President's acute care catastrophic proposal to include coverage of long-term care services in order to address the greatest catastrophic risk to which the elderly are exposed.

AAHA is a national nonprofit association whose membership embodies the entire continuum of long-term care. AAHA represents over 3200 nonprofit providers of nursing home care, housing, health-related facilities, continuing care retirement communities, and community services including such programs as adult day care, home health, and meals-on-wheels. Through direct delivery of services in their facilities, AAHA members serve over 500,000 elderly individuals annually, while at the same time striving to meet the needs of an additional 1,000,000 older people annually through their various outreach programs. Religious organizations sponsor 75% of AAHA members, with the remaining members sponsored by private foundations, fraternal organizations, government agencies, unions, and community groups committed to providing quality services for their residents and for elderly persons in the community at large.

AAHA and its members comprise an important part of the nonprofit, voluntary sector which is increasingly being asked to fill the widening gaps in inadequate public programs. The voluntary sector is taking this challenge very seriously as illustrated, for example, by the development of nonprofit continuing care retirement communities, a comprehensive model of managed care which includes housing, healthcare and supportive services. This model which is gaining attention from public policy decisionmakers, is detailed below in the Private Sector Initiatives section.

Coverage of long-term care costs and the provision of adequate and varied long-term care services, however, must firmly remain a joint responsibility of both the public and private sectors, with Congress taking a leadership role in assuring that the long-term care needs of the elderly are met.

OVERVIEW

Catastrophic coverage for long term care, as well as incremental improvements in Medicare and Medicaid, are certainly two of the most difficult issues facing this Subcommittee and the Congress. First, the demographics of aging portray the stark reality of the need for long-term care coverage, now and in the future. Both the projected growth in aggregate numbers and the increasing proportion of the elderly to the general population are startling. In 1984, about 28 million Americans were age 65 and over; by 2010, this age group will increase to 38 million and by 2050, more than 67 million individuals will be 65 and over. While the elderly comprise about 12% of the population currently, one in seven Americans will be at least 65 years old by 2010 and in 2050, one in five will be 65-plus. Moreover, those most likely to require long-term care services, the 85 and over age group, is the fastest growing segment of the aged population. Currently comprising about 1 percent of the total population, by 2010, this "old-old" group will total 6.5 million (2.3%) and by 2050, their numbers will grow to 16 million or 5.2% of the total population.

Concomitant with its growth in numbers, this segment of the population has attracted increased attention from the media, Congress, and the general public. One outgrowth of this magnified visibility has been the emergence of the "myth of the greening of the aged" which credits expansion of Social Security and the existence of a network of other public social programs with the elimination of poverty among the elderly. While it is true that some progress has been achieved in reducing the pervasiveness of poverty among the aging, it is also true that poverty remains more prevalent among this group than among any other group of American adults. It is also the case that the likelihood of being impoverished rises sharply with age. The poverty rate of the population aged 85 and over is more than twice as high as that for persons aged 65 to 69. Using the official poverty line for individuals 65 years of age or older, as defined by the U.S. Census Bureau for 1985, there are currently 3.5 million elderly men and women who are "officially poor". If the "economically vulnerable" are included, those living at an income level between 100 and 200 percent of the poverty line, the number rises to 11.5 million, 42% of the total elderly population.

At the same time that many elderly face a precarious income situation, their need for long-term care services increases. Due to several factors, including advances in medical science and life-saving technology during this century, there has been a radical change in the form of illness and disease afflicting these individuals. What was previously a predominance of acute care conditions has now been replaced by a prevalence of long-term chronic illness. There are currently 1.5 million people over the age of 65 in nursing homes. By the year 2000, the number in need of institutional long-term care will rise to [illegible] million. Another 2.8 to 3 million persons age 65 years and over who need assistance in daily living activities (e.g., walking, bathing and eating) and/or with home management activities (e.g., cooking) reside outside an institution in the community. For these individuals, informal care provided by family and friends is the primary source of assistance. Some services, such as home care and adult day care, help to relieve the burden on these informal caregivers who are often elderly themselves. But the lack of or limited coverage for these services under public programs, as well as gaps in the availability of these services, makes it clear that these elderly individuals are not receiving all the long-term care services they need.

Clearly, the magnitude of these data is staggering. But Congress' response must not be to dismiss the issue of coverage for long-term care as beyond our control and ability to address, however tempting it may be. Rather, these facts demand that action be taken now to address the needs of the current elderly and to plan and prepare for the future that we face [illegible].

THE CURRENT STATUS OF PUBLIC PROGRAMS

Action on long-term care coverage also may appear overwhelming because the status of such coverage today is so extraordinarily poor. AAHA now turns its attention to Medicare and Medicaid, the key public health care programs for the elderly.

Medicare: The Myth of Long-Term Care Coverage

Medicare, the primary public program providing the elderly with protection against health care costs, was created with and retains a major acute care bias. While it is estimated that Medicare outlays for services will total about $84.5 billion in fiscal year 1988 (using the 1987 current services baseline), less than 1% will go to cover the costs of skilled nursing home care (SNF) and only about 3% will be used to reimburse for home health care services.

The paucity of covered services is not surprising given the extremely restrictive nature of the SNF and home health benefits under Medicare. To be eligible for either of these benefits, Medicare beneficiaries must require skilled services. For nursing home care, a 3-day prior hospitalization requirement exists, and for home health care, the individual must meet a strict "homebound" requirement as a threshhold to Medicare coverage. Practical experience with these benefits indicates that coverage criteria are being applied in an extremely stringent manner by Fiscal Intermediaries who process claims as contractors of the Health Care Financing Administration. In fact, the coverage decisions appear to become more and more constrictive, even as many Medicare beneficiaries are being discharged faster and in very frail condition from hospitals under the DRG prospective payment system. In some cases, adverse coverage decisions are passed on to long-term care providers, who must then absorb the costs of care already given. Needless to say, this discourages providers from enthusiastic participation in the Medicare program and decreases the availability of these services to Medicare beneficiaries.

In addition, Medicare beneficiaries may face continuing problems trying to determine what the law actually includes as benefits at any given time. For instance, the Omnibus Budget Reconciliation Act of 1986 contained modest expansions of Medicare coverage for occupational therapy, vision care, and physician assistant services. The Administration's FY 1988 budget, released last month, calls for repeal of these expansions in coverage. This see-saw strategy with the Medicare program may be effective for purposes of federal budget negotiations, but for the Medicare beneficiary, these political maneuvers are sources of confusion and frustration.

Medicaid: The Program of Last Resort

In sharp contrast to Medicare, long-term coverage under the Medicaid program better addresses the true care and service needs of the elderly. It recognizes that the need for long-term care most often is not tied to recovery from an acute care illness, but results from chronic impairments which require care and services over an extended period of time. However, serious limitations exist under Medicaid.

Most critically, this program is severely means-tested such that only the very poor have access to the program. Last year, 2.2 million elderly individuals with incomes below 100% of the federal poverty level were ineligible for the program. As a joint federal-state program which is administered by the states, eligibility categories and requirements vary significantly by state. Each state must have a "categorically needy" category where eligibility is measured by a person's income and assets. While income and assets standards are not uniform across states, the restrictive nature of these standards is illustrated by the thirty-five states and the District of Columbia which employ the federal SSI standards for determining who is "categorically needy": income of no more than $336 per month for a single person and $504 for a couple in 1986 and liquid assets of no more than $1700 for a single person and $2550 for a couple; assets excluded from eligibility determinations include a person's principal residence, $2000 of personal effects, burial arrangements valued at no more than $1500, and a car valued at no more than $4500.

AAHA does commend the Congress for enacting an "optional categorically needy" eligibility category for Medicaid in OBRA of 1986. This provides promise for those currently uncovered who have incomes below 100% of the federal poverty guidelines but above existing state standards for eligibility. Since this OBRA provision is framed as a state option which will not be available until July 1, 1987, it frankly is too soon to assess its impact.

At their option, most states, but unfortunately not all, also have established a "medically needy" category whereby individuals with high health care expenses relative to their incomes may be eligible for Medicaid. These individuals also must meet the state's medically needy resource standard, requiring a phenomenon commonly known as "spend down". Thus, for many elderly individuals, Medicaid eligibility is achieved only after a life-time of savings is depleted.

The most tragic result of this stringent system can be called "spousal impoverishment." For elderly couples where one spouse needs nursing home care and the other remains at home, a complicated system using "deeming rules" and a restrictive "spousal maintenance allowance" often requires both the at-home spouse and the institutionalized spouse to become impoverished before Medicaid coverage for the nursing home care is achieved.

Assume that the wife remains at home and her husband requires care in a nursing home. Assume as well that most or all of the couple's income and assets are in the husband's name or held jointly. Under the current system, for the month in which the husband first enters the nursing home, Medicaid considers all of the couple's income and resources to be fully available to the institutionalized spouse; following this month, the two spouses' income and assets are looked at individually in recognition that the at-home spouse needs to support herself in the community. However, as assumed above, if everything is in the husband's name, then all income and assets are considered available to the husband for paying the cost of his nursing home care. In this event, the wife can receive a "spousal maintenance allowance" which is likely to be less than $400 per month and in Indiana, for example, is only $258 per month. It is impossible to imagine that this amount is sufficient to cover rent and utilities, let alone food for the at-home spouse. The husband, using income and assets in his name or held jointly, will continue to "spend-down" to Medicaid eligibility.

Some states are trying to address this unjust situtation by changing their property laws or refusing to apply the deeming rules. In some cases, relief has been sought in the courts, with some courts ruling that court-ordered support awards are not to be considered available to the institutionalized spouse for determining Medicaid eligibility. This piecemeal approach, however, is inadequate to address the problem; federal reform is needed.

Medicaid's second significant limitation involves the types of long-term care services covered by the program. Admittedly, Medicaid has an institutional bias, providing long-term care coverage primarily in the nursing home setting. This coverage is essential, however, and effectively is the only source of public coverage for nursing home care. Even with Medicaid's substantial contribution, in 1984, elderly individuals' out-of-pocket expenditures for nursing home care totalled over $12.5 billion, accounting for 50% of all spending for this type of care. With the growth of the elderly population and the 85-plus age group in particular, the need for Medicaid coverage of nursing home care will become even more critical.

The problem is that coverage for such services as home health care, adult day care, and homemaker-chore services is also important to meet the varied needs of an increasing aging population. Implementation of the Medicaid Home- and Community-based Services Waiver program has been an improvement in this area, with about 43 states having at least one waiver under the program. HCFA's strict interpretation of budget neutrality and various regulatory restrictions, however, have served to limit the number of individuals who can be served under the waiver programs. In addition, as a waiver program, states need not make selected noninstitutional long-term care services available on a state-wide basis. Thus, many Medicaid-eligible individuals living at home and at risk of institutionalization still do not have access to noninstitutional long-term care services even in states with 2176 waivers.

CATASTROPHIC COVERAGE FOR LONG-TERM CARE

AAHA urges this Subcommittee and the Congress to look beyond the President's proposal for catastrophic coverage of acute illness expenses and to consider alternatives which provide meaningful protection against the risk to which the elderly face the greatest exposure: the catastrophic costs of chronic or long-term care services.

AAHA commends the President for his proposal which would aid older Americans exposed to the catastrophic costs of acute illness requiring extended and/or multiple hospital stays. Clearly, such illnesses pose an unmanageable financial burden for all but the richest Medicare beneficiaries. Notwithstanding the need for protection against excessive acute care expenditures, however, AAHA has three primary concerns regarding the President's proposal. These concerns include the limited number of Medicare beneficiaries standing to benefit from the President's proposal; the failure to address the risk to which the elderly face the greatest exposure; and the erroneous perception likely to result on the part of the elderly that the President's program will address the problem of catastrophic health care expenditures.

Limitations of President's Proposal

AAHA recognizes the need for protection against the financially ravaging effects of extended acute care utilization. The financial burden associated with such utilization can be attributed to several aspects of Medicare's program design. First, under Part A of Medicare, full coverage for hospital care is provided only for the first 60 days of a spell of illness -- after a first day deductible has been met. In 1987, this deductible is $520. For days 61 through 90, the beneficiary is subject to a daily copayment equal to one-fourth of the first day deductible, or $130 this year, and a copayment of $260 per day for each of the 60 lifetime reserve days used. Beneficiaries unfortunate enough to exhaust their lifetime reserve days are responsible for full payment of hospital costs. Because the Part A deductible is set by a formula to approximate the average Medicare payment per day of hospital care which is indexed for inflation annually, these charges have been increasing steadily since the inception of the Medicare program.

A second design issue is related to copayments and deductibles incurred by Medicare beneficiaries under Part B and open-ended liability for unassigned claims for physician payment. Under Part B of the Medicare program, beneficiaries are required to pay an initial deductible ($75 in 1987) and a 20% copayment for all Part B covered services. Furthermore, in cases where physicians do not accept assignment, what Medicare considers to be "reasonable costs" for services as payment in full, beneficiaries are liable for the difference between the phyician's charge and Medicare's approved payment.

A third limitation in the Medicare program design pertains to the absence of coverage of certain services such as outpatient prescription drugs; vision, hearing and dental care; and a number of preventive health care services. For example, in 1984, over $3.5 billion was spent on prescription drugs for the elderly; 80% of these costs were paid for directly out-of-pocket.

A fourth and, in our judgement, the most critical shortcoming of the Medicare program design is the limited long-term care coverage available under this program. While Medicare technically provides up to 100 days of nursing home care, as explained earlier, the restrictiveness of the eligibility requirements severely constrains the elderly's access to Medicare nursing home benefits. Even in cases where individuals are eligible for coverage, after the first 20 days of care, the elderly are subject to a copayment of one eighth the average cost of a hospital day, or $65 in 1987. Given an average per diem charge of $60 per day, in many cases, the coinsurance rate renders the elderly fully responsible for the cost of care.

Given the several limitations characterizing access to Medicare benefits, a very small proportion of the Medicare population stands to benefit from the President's proposal. According to the House Select Committee on Aging, this proposal will expand coverage to less than 3% of Medicare beneficiaries. This limited expansion can be attributed to several factors. First, of the total health care expenditures incurred for inpatient hospital services, the elderly pay for only 5.6% of these costs out-of-pocket. Second, the President's proposal is designed to provide protection in an area that already is substantially covered by private supplemental insurance policies. Fully 70% of individuals over 65 have Medicare supplemental policies. According to the Bowen Report on Catastrophic Illness Expenses, for individuals with supplemental insurance protection who have one hospital admission of less than 61 days, the average out-of-pocket expense for Medicare services is $474; the average annual out-of-pocket expense for individuals whose time in the hospital exceeds 60 days is $1,698 for those with private supplemental insurance. In both cases, these out-of-pocket costs still fall below the $2000 threshold in the President's proposal.

AAHA also is profoundly concerned that the fanfare surrounding the introduction of the President's proposal -- and the President's personal assurance that his proposal will provide the last measure of safety and protection required by the elderly -- will lead Medicare beneficiaries to the erroneous conclusion that their concerns regarding catastrophic health care expenses are no longer warranted. This perception could not be farther from the truth.

AAHA RECOMMENDATIONS

AAHA seriously urges this Subcommittee and the Congress to consider several alternatives to expand the President's proposal which would provide meaningful protection against the risk of expenses associated with long-term chronic illness. These alternatives include both public and private sector approaches and range from comprehensive reform of the long-term care financing and delivery system to proposals offering more limited measures of additional protection to selected segments of the elderly population.

Public sector alternatives recommended by AAHA for Congressional consideration include comprehensive protection for acute and chronic health care services through an extension of the Medicare program; expansion of the President's proposal to include recommendations proposed by Secretary Bowen relative to long-term care expenses; an extension of waiver authority for the Social Health Maintenance Organization demonstration; and a series of incremental improvements to the Medicare and Medicaid programs. Private sector alternatives proposed by AAHA include activities promoting the development of private long-term care insurance mechanisms ranging from the expansion of coverage under individual indemnity policies to the development of case-managed, integrated systems of acute and long term care services.

Comprehensive Health Insurance

Several proposals have been introduced in Congress in recent years which are designed to correct the fragmented nature of our long-term care delivery system and to fill in gaps in services. Most recently, Congressman Pepper has introduced H.R. 65, "Medicare Part C: The Catastrophic Health Insurance Act of 1987". This proposal would provide all Medicare beneficiaries with comprehensive catastrophic health care coverage currently unavailable under private or public insurance. Benefits would include unlimited hospital stays, comprehensive long-term care services managed by geriatric specialists, and benefits currently uncovered by Medicare, such as vision, hearing and dental care, prescription drugs and disease prevention services.

Medicare Part C is intended to incorporate the unique advantages of models such as the social health maintenance organization and preferred provider organizations which are characterized by inherent cost-savings features. These features include single-point entry into the delivery system, case-management of care, and provider risk-sharing mechanisms. Through the integration of acute and chronic care services, cost efficiencies could be achieved by the substitution of less costly services; greater assurances regarding quality could be effected through the coordination of care by a single provider. Furthermore, services under Part C are projected to be budget neutral, since the additional premiums necessary to fund Part C services would be paid for by beneficiaries with income currently paid to private insurers for Medigap policies.

AAHA strongly supports in concept the idea of comprehensive coverage of health and long-term care services for the elderly. Three questions in particular, however, are of concern to AAHA relative to the comprehensive proposals introduced before the Congress. First, additional information regarding the economic assumptions used to determine the premium rates under Medicare Part C would help to alleviate concerns regarding long-run program costs. While the $800 per year premium estimated under the Pepper proposal would be within most elderly persons' ability to pay, and in fact, would reduce by half the average out-of-pocket expenditures currently paid by the elderly, it is imperative to assess the long-run viability of such premium levels before older people dispense with existing coverage provided under private plans.

Second, since beneficiaries would be required to receive their health care services from providers contracting with Medicare, it is possible that the elderly's freedom of choice to choose their own physicians would be restricted in cases where their current providers did not contract to provide services at Medicare rates. A third and related concern deals with reimbursement policies set under the Medicare Part C program. While providers choosing to contract with Medicare clearly have the option of contracting on a capitated or fee-for-service basis, fees will be set in advance by Medicare in both cases. Our current experience with public funding of long-term care services under the Medicaid program raises serious questions about the adequacy of reimbursement under a Medicare Part C program. Per diem rates for Medicaid nursing home care historically have failed to reflect the true cost of care, nor have they kept pace with inflation. As a result, our members consistently experience cost over-runs in providing service to such residents. Under the Medicare Part C program, with fewer residents admitted on a private pay basis, our members would be even more hard-pressed to maintain the high quality standards distinguishing nonprofit providers within the constraints of a system supported predominantly through public funds.

Accordingly, while AAHA fully supports the concept of comprehensive health insurance for the elderly, support of legislative proposals is contingent upon adequate funding of long term care services.

Bowen Long Term Care Initiatives

In the absence of a comprehensive national health care program for the elderly, AAHA also proposes several alternatives of a more limited scope. Since the President's proposal derives from the recommendations proposed by DHHS Secretary Otis Bowen, our first alternative is to suggest that the Congress consider the Secretary's full recommendations for catastrophic illness expenditures for the elderly, which included several provisions related to long-term care.

It is important to acknowledge at the outset that many of the Secretary's provisions are targeted toward specific segments of the elderly population. Nonetheless, we support the Secretary's proposals as important first steps toward solving the problem of catastrophic health care costs. In addition, while some of the provisions recommended by the Secretary disproportionately favor the elderly in higher income brackets, we believe that fewer of these individuals would be forced to spend down to Medicaid if provided adequate incentives to plan ahead for their long-term health care needs. Below is a summary of the Bowen recommendations for long-term care protection supported by AAHA.

1. The Federal Government should work with the private sector to educate the public about the risks, costs, and financing options available for long-term care, as well as the limitations of coverage for such services under Medicare and Medigap supplemental insurance. Elements of a campaign might include:
   - Use of radio, television, and printed material targeted to both the elderly and their families, providing information regarding risks, costs, and financial protection measures.
   - Continued use of currently planned official mailings to Social Security and Medicare beneficiaries to clarify current program coverage for long-term care services.
   - National coordination of, and assistance for, State-led efforts to assist consumers in understanding and selecting financial protection for long-term care services.
   - Educational and promotional efforts on private financing of long-term care directed toward long-term care insurers and providers.

2. The Federal Government should encourage personal savings for long-term care through a tax favored Individual Medical Account (IMA) combined with

insurance, and amend Individual Retirement Account (IRA) provisions to permit tax-free withdrawal of funds for any long-term care expense.

3. The development of the private market for long-term care insurance should be promoted in three ways:

   - establish a 50% refundable tax credit for long-term care insurance premiums for persons over age 75 -- up to an annual maximum of $100.

   - provide the same favorable tax treatment for long-term care insurance reserves as is now the case for life insurance.

   - remove 1984 Deficit Reduction Act (DEFRA) barriers to the pre-funding of long-term care benefits provided by employers to retirees.

4. The Federal government set an example for private employers and care providers by offering employee-paid long-term care group insurance as an option under the Federal Employees Health Benefits Program.

The first recommendation addresses a long-standing barrier to the expansion of private insurance mechanisms for long-term care services. Numerous studies conducted by private organizations such as the American Association of Retired Persons and various private insurance carriers demonstrate that the American public consistently underestimates the risk of chronic illness requiring costly long-term care services and dramatically overestimates the amount of existing protection available under Medicare and private supplemental insurance policies. A survey conducted by the National Center for Health Services Research revealed that, of the respondents who had considered the need for long-term care services, only 14.5% considered this risk very likely. Furthermore, the majority of consumers surveyed expected long-term care costs to be covered by Medicare and fully half of the respondents holding Medicare supplemental policies believed that the costs of nursing home care were covered by their private policies.

These studies demonstrate the critical need for consumer education regarding the risks of chronic illness and the protection currently available through public and private insurance. Accordingly, it is clear that, in the absence of a nationally mandated program of insurance, consumer education will be a critical factor affecting consumers' willingness to increase their insurance protection through private means.

[illegible] also believes that the various tax incentives proposed by Secretary Bowen represent promising vehicles for encouraging consumers to accept greater responsibility for increasing their health care protection. Recommendations permitting tax-free withdrawal of funds from Individual Medical Accounts and Individual Retirement Accounts for expenditures for long-term care services would provide consumers greater incentives for personal savings. Similarly, the establishment of a 50% refundable tax credit for long-term care insurance premiums for persons over the age of 55 may encourage more older people to purchase private insurance protection at an age when such coverage remains reasonably priced. Furthermore, the use of a tax credit — as opposed to a tax deduction -- is significant, since tax credits would more significantly benefit the low income elderly. This proposal could be further enhanced if the tax credit maximum, currently proposed at $100, were based on a sliding scale. Since most long-term care insurance policy premiums are rated according to age at time of purchase, individuals buying such policies at age 75 pay much higher premiums and would receive far less benefit from the tax credit than those purchasing policies at age 55.

The Secretary's long-term care proposals also included significant enhancements for insurers and employers to promote the development of private insurance protection. If insurance company reserves for long-term care insurance were exempt from federal taxes, premiums for insurance policies could be reduced by 11% for those purchasing policies at age 65; and by one third, for persons purchasing policies at age 55. Lower premiums could significantly increase consumer demand for long-term care insurance and spur private product development in this market. Similiarly, tax exemptions on employers' insurance reserves for post-retirement medical benefits would create employer incentives to offer this option.

AAHA also supports the Bowen recommendation that the Federal government offer employee-paid long-term care group insurance as an option under the Federal Employees Health Benefit Program. Beyond the direct benefit to Federal employees, over time, this program would generate invaluable data regarding utilization patterns and health care expenditures which could be used to develop actuarially sound and fiscally responsible premium structures for private long-term care insurance policies.

Extension of S/HMO Waivers

Public policy makers clearly are looking to providers and insurers for new initiatives in long-term care financing and delivery which will reduce and not expand the public burden of chronic illness expenses. Such initiatives include private long-term care insurance, more comprehensive Medicare HMOs and other types of catastrophic illness protection such as social health maintenance organizations. Critical to the expansion or improvement in financing and delivery, however, is reliable data answering the following questions:

- How should benefits be designed in terms of covered services, eligibility conditions, benefit levels, renewability and coinsurance?
- How can benefits be managed in ways that control costs and assure good quality and access?
- How much will benefits cost for services, marketing and administration?
- What organizational models can most efficiently supply the delivery system, marketing expertise and economics of scale required?
- How can acute and chronic care services effectively be integrated?
- How should services be reimbursed in ways that give providers efficiency incentives yet are sensitive to selection bias?

To date, lack of experience and insufficient data regarding risk controls have hindered development of private long-term care insurance mechanisms. The fear of adverse selection, open-ended liability and insurance-induced demand have prevented insurance companies from offering the types of insurance products necessary to protect against the catastrophic costs of long-term illness. In the absence of utilization data adequate to develop actuarially sound pricing structures for long-term care insurance policies, insurance companies have offered extremely limited benefit packages for chronic illness services. Where policies do exist, premiums have been prohibitive to older people living on reduced retirement income.

To assist in providing insurers and providers with accurate data to answer these questions, AAHA strongly urges the Congress to support the request submitted by the Social Health Maintenance Organization Consortium for an extention of the S/HMO demonstration until 1991. The current waiver schedule calls for the sites to cease new enrollment in the fall of 1987 and to shut down completely in the fall of 1988. Due to marketing problems early on, enrollment in this demonstration has been slower than anticipated and the current schedule will not permit adequate time and experience to test the S/HMO hypotheses under full enrollment. Since administrative and overhead costs have exceeded the projected levels due to a smaller than expected beneficiary pool, the early results in this area are misleading. A more critical factor to be considered, however, is the benefit of longer range experience in the study of the management of long-term care benefits; the interaction of acute care and long-term care service utilization; evaluation of quality of care in a case-managed care system; and service delivery design issues.

The S/HMO sites have created the first insurance risk pools for comprehensive managed chronic care benefits and are in the process of exploring how to target efficiently and effectively these services to members. The experience gained through this demonstration will provide invaluable information to private insurers and providers interested in designing new financing and delivery models. Initial research demonstrates hospital utilization considerably under fee-for-service levels and chronic care utilization close to projected budget levels. Furthermore, downward substitutions of services including direct SNF admission in lieu of hospitalization and early discharge with home care services have been used successfully. Mid-level practitioners, such as geriatric nurse practitioners are being used successfully both in clinics and for coordination of nursing home residents' care.

Substantial public and private investments already have been made to the S/HMO demonstration. AAHA believes that it would be a serious mistake to dismantle these projects before we have had adequate time to realize the benefits of the research being conducted. Brandeis University, which has responsibility for administering the S/HMO project, has requested a 3.5 year extension of waivers through 1991. HCFA has deferred its decision until July of this year, just three months before the S/HMOs must cease enrollments. In order to accommodate the elderly individuals currently being served by the S/HMOs, these projects will need to begin planning for beneficiary conversion in the near future. Accordingly, it is imperative that the projects determine as soon as possible the potential for being granted the extension.

Incremental Improvements in Medicare and Medicaid

While AAHA urges that catastrophic coverage for long-term care be addressed by this Congress, we do recognize the enormity of this task. Therefore, AAHA also would like to recommend some incremental and relatively minor improvements in Medicare and Medicaid that would serve to render existing benefits more predictable and help to lessen the burden of the elderly's long-term care costs:

Medicare

- The Medicare budget cuts proposed by the Administration for FY 1988, including the proposed repeal of benefits provided under the 1986 Reconciliation Act should be rejected.

- Congress should act to implement a system of prior authorization for Medicare SNF and home health care benefits. A study currently underway at HCFA will have results of demonstration projects on this issue by early next year. A sound prior authorization system would go far to make coverage much more predictable for both beneficiaries and providers.

- Criteria and standards should be added to the HCFA Contractor Performance Evaluation Program (CPEP) which measure the accuracy and consistency of claims processing contractors with respect to Medicare benefits.

- H.R. 550, The Medicare Adult Day Care Amendments of 1987, should be introduced and adopted in the Senate as an important but modest step forward in improving access to adult day health care for those Medicare beneficiaries at risk of institutionalization. The bill would provide coverage under Part B for up to 100 days per calendar year for adult day care services rendered by a medically-oriented program; eligible beneficiaries would be required to pay a copayment of $5.00 per day.

- Due to inconsistent interpretations of the definition of "intermittent care" used for coverage decisions under the Medicare home health benefit, the definition should be clarified by adding "daily care for up to 90 days, with monthly physician certification".

Medicaid

- The Administration's Medicaid cap proposal for FY 88 should again be rejected.
- Current Medicaid eligibility criteria which has the harsh effect of causing "spousal impoverishment" should be modified by: 1) ending deeming on the day one spouse enters a nursing home; 2) setting a minimum federal spousal maintenance allowance, instead of the current federal ceiling approach; and 3) requiring states to exclude from consideration for eligibility a reasonable amount of liquid assets owned by the institutionalized spouse or held jointly in order to preserve some assets for the spouse left at home.
- Noninstitutionalized long-term care services currently only available

in a limited way under the Medicaid Home- and Community-based Waiver program (e.g., adult day care) should be made optional benefits under Medicaid.

- The use of Medicare reimbursement methods as an "upper limit" on Medicaid nursing home payments should be prohibited. States in which the costs of providing skilled nursing care have already exceeded the Medicare rate, have used the "upper limit", methodology to ratchet down these Medicaid rates. Many of these State rates no longer bear a close relationship to the costs they purport to cover and thus serve to discourage providers from responding as they would like to the long-term care needs of the poor elderly.

PRIVATE SECTOR INITIATIVES

Recognizing the growing need for catastrophic illness protection for long-term care services, and the apparent reluctance of the public sector to accept added responsibility in this area, the private sector has taken the lead in spearheading many innovations in long-term financing and delivery models. Nonprofit providers, who represent 90 percent of the continuing care retirement communities in this country, are experimenting with new versions of this self-insured delivery model. Other case-managed, pre-paid health care systems are developing variations of the social health maintenance organization model. In addition, virtually every major commercial insurance carrier, and smaller carriers as well, are engaged in sophisticated market research to test the feasibility and appeal of various coverage models. Examples of these innovations are detailed below.

Continuing Care Retirement Communities

CCRCs are organizations that provide housing, health care (including long-term care), and a variety of supportive services to people of retirement age. These communities provide increasing levels of care that meet the needs of individual residents as they age, including independent living and various types of health, social and nursing care services. Most CCRCs have been built in the last two decades, are owned and operated by nonprofit organizations, and are affiliated with religious and other private organizations.

Two types of fees are generally required by all continuing care communities: a lump sum entry or endowment fee paid upon entrance to the facility and a monthly service fee. The amount of both fees vary from community to community depending upon the type and size of residential unit selected, the variety of services included in the contract and the number of people in the unit. Entry fees range from $30,000 to over $100,000 and monthly fees average between $600 and $2,000 a month. The combination of these fees generally covers all the services provided under the contract agreement. Numerous services and amenities may be included in the fees, with additional services available for purchase by residents on a fee-for-service basis.

While a wide variety of CCRC contract arrangements are now being offered, two distinct models have begun to emerge. The traditional or insurance-type plan and the fee-for-service model. The traditional or insurance model virtually insures that all of a resident's current and future needs including meals, services, and health care (including long-term nursing care) will be included in the fees paid by the resident. If and when a resident requires services in the health care center or moves permanently to that facility, they will continue to pay the fee they were paying while in their independent living unit. Under this arrangement, the costs of health care are spread among all residents of the community, regardless of their individual needs, and insures the availability of long-term care for all residents as necessary. This cost sharing approach is much like an insurance plan where the costs of providing care are shared by all residents, regardless of their individual needs, and insures that individual residents will never spend down their assets nor become dependent on Medicaid funding.

The fee-for-service CCRC model provides a continuum of care and many of the services offered in traditional continuing care facilities, but requires that many services, including nursing care be paid for on a fee-for-service basis. In these facilities, once a resident requires services in the nursing facility, they are required to pay a per diem rate. Many facilities provide a set number of days (usually between 15 and 60) that residents receive at their regular monthly fee; once these days are depleted, however, residents are required to pay the per diem rate for care they receive. In some cases, this per diem rate is discounted so that residents are not paying the full cost of care.

Facility-Based Private Insurance Mechanisms

The growing popularity of the fee-for-service CCRC model has spurred a number of organizations and private insurance carriers to explore the feasibility of self-insurance and re-insurance mechanisms to increase the existing protection residents of CCRCs receive by virtue of their contractual arrangements with providers. The American Association of Homes for the Aging has established a Task Force on Long-Term Care Insurance to examine facility-based insurance mechanisms which could increase coverage for long-term care services ranging from supportive services, such as home health care to skilled nursing facility services. Insurance options range from limited "stop-loss" policies which protect residents and providers from exposure to aggregate excesses in the use of skilled nursing services to comprehensive policies covering a wide range of chronic care services.

In addition to the direct benfit of increased coverage of services for current residents, AAHA believes that 're-insurance" of CCRC services may enable providers to lower entrance and monthly service fees, thus enabling a wider range of older people to have better access to care through this model. A number of private insurance carriers including Metropolitan, the Provident, and Aetna currently are developing such insurance mechanisms.

AAHA also believes that the CCRC insurance product could pave the way for expansion to other types of service models. For example, the Health Policy Center at Brandeis University recently received funding to test a concept called "Life Care at Home". Patterned after insurance moddels such as the continuing care retirement community and the social health maintenance organization, this plan combines risk-pooling for long-term care and other traditional life care benefits with the independence of living in one's own home.

Second Generation Approaches to Traditional Insurance

A number of other "second generation approaches" to traditional insurance mechanisms also are being explored by the private sector. At least 16 members of the Health Insurance Association of America offer individual indemnity policies that cover a minimum of one year of nursing home and/or home health benefits. The American Association of Retired Persons is testing a product underwritten by Prudential that provides up to four years of nursing home coverage, as well as home health care. Problems continuing to present barriers to further expansion of indemnity policies include insufficient data upon which to assess risk, condition benefits and structure premiums which are both actuarially sound and which can include an inflation index on benefit levels.

Private insurance carriers also are beginning to explore a range of employer-based insurance mechanisms, with benefits paid by employees alone or with joint contributions from employers and employees. The Travelers Companies have introduced an employer-based product offering nursing home, home health, and adult day care benefits which has guaranteed portability and can be used to insure employees' parents as well as themselves. Northwestern National Life is demonstrating an employer-sponsored, pre-paid, capitated health plan based on the S/HMO model. Harvard University also has announced that it will test a long-term care insurance plan for university employees.

Other private insurance efforts include the development of a wide array of financial accumulation models. For example, Northwestern National Life is developing a wide array of models such as life insurance with long-term care riders, portable pensions and other plans that expand upon existing insurance mechanisms.

This list of private sector initiatives is indicative of the tremendous momentum gathering for the further refinement of various experimental approaches to long-term care financing. Each of the above efforts will assist in answering the questions posed earlier regarding benefit levels, system design and sound pricing structures. Long-term care financing trends clearly are moving in the direction of: 1) broader risk pools which are representative of the general older population; 2) pre-funding of liability to provide adequate time for the accumulation of insurance reserves protecting private carriers from open-ended risk; 3) the integration of acute and chronic care services, where risk and costs can be controlled through the increased substitution of less costly services, careful monitoring of health care utilization and more appropriate client/service matching; and 4) case-managed care systems which enhance each of these controls. Various combinations of these features can be found both in public and private sector initiatives.

AARP is optimistic that the private efforts to improve the financing and delivery of long-term care services detailed above will lead to greater efficiencies in service delivery and expanded access to much needed long-term care services.

CONCLUSION

We have entered a watershed period in the development and exploration of alternatives to our nation's currently fragmented system of long-term care services which poses severe access problems for the elderly. Federal responses have included the establishment of the Bowen Commission to study catastrophic illness expenses and the DHHS Task Force on Long-Term Health Care Policies.

STATEMENT OF PAUL WILLGING, EXECUTIVE VICE PRESIDENT, AMERICAN HEALTH CARE ASSOCIATION, WASHINGTON, DC

Dr. WILLGING. Thank you, Mr. Chairman. I do appreciate the opportunity to testify before you and the committee today. I would like to start, as have my colleagues, in commending you and this committee for having focused on what is indeed one of the most critical issues facing this country, the issues of long-term care, both its financing and its quality.

I would have to underline the comments made by my colleague, Mr. Goldberg, that laudible though the President's proposal may be, it does not deal with catastrophic health care expense; it nibbles on the edge of catastrophic health care expense. Eighty percent of all catastrophic related health care dollars spent by the elderly are spent on long-term care services. Hospitals are only 10 percent; physicians six. And so, I think it is laudible that this committee has decided to focus on what is truly the issue with respect to America's elderly, the issue of long-term care.

And I think it is, in fact, time for this country to come to grips with this issue, no matter how complex, no matter how horrendous it may appear at first blush. While we are doing so, though, Mr. Chairman, I think it also important that we stop the slide in terms of those existing programs put in place by this Congress in 1966 to deal, however badly or well, with the issues of long-term care; Medicare being one, Medicaid being the other.

Medicare was admittedly in 1966 not designed as a long term care program; it was designed as a post-hospitalization program following the Medicare hospital benefit. But given the recent actions, primarily by the Executive Branch, and inaction, if you will, by both parts of Government, we find that even that initial purpose set up for the Medicare program is not really being met.

We have a limited number of providers of nursing home services who can provide reasons for participating in the Medicare program. Less than one-third of certified nursing homes participate in Medicare. Indeed, 500 nursing homes across the country provide over half of all of the SNF benefits for a variety of reasons: the nature of the reimbursing that, even with DRGs staying the same, cost reimbursement for nursing homes; and the nature of coverage decisions, which are becoming increasing arbitrary and capricious, be it vis-a-vis nursing homes, be it vis-a-vis home care.

And we would hope during this session of Congress that you, your committee, and your colleagues on both the House and Senate sides would look at ways of at least taking the Medicare program back to its initial intended purpose with respect to long-term care. I think it also important as we look to the future in terms of financing long-term care that we not allow the existing major program put in place to deal with long-term care to suffer the kind of assault that has been perpetrated on it by the Administration over the past three or four years.

The President's budget, as you know, Mr. Chairman, would remove $8 billion over a five-year period of time from the Federal commitment to long-term care. Fifty percent of Medicaid is long-term care. Turning it into a lock grant capped by certain indices would, in fact, have the result by OMB's own calculations, of a massive reduction in the Federal commitment. But while we do that, I think it is time—and I would share the views of my colleague, Mr. Halamandaris—it is time that we not postpone any longer our attempts to deal with what has been referred to as the most critical health care issue facing the elderly.

Let us not delude ourselves into thinking that by dealing with hospital and physician catastrophic health care costs we have at all dealt with the primary issue, which is long term care. I think there are a number of recommendations that should be seriously analyzed.

I commend to this committee—and I know it has already received a fairly large amount of favorable press on both the House and Senate sides. Secretary Bowen's own recommendations with respect to long-term care. In his report to the President, he pointed out that the most likely event faced by the elderly in terms of catastrophic health care expense is long-term care. He made 12 recommendations to the President, all of them worthy I think of serious consideration.

I know it has been said that this cannot be the time to deal with this issue, that it is too complex, that it is too horrendous, that its ramifications are much too broad; but Mr. Chairman, we are already dealing, even in terms of resources, with the problems of long-term care. The question is not: Do we deal with it? The question is not: Do we find the resources? The question is how we spend those resources. Today, this country, perhaps through default more than anything else, is spending those resources through as demeaning and dehumanizing and degrading a program ever devised by man—the Medicaid program.

Surely, we as a society can come up with a better approach which in effect allows our elderly, if they need long-term care, not to have to divest themselves not ust of their resources, but of their human dignity and their self-respect as well. Thank you very much.

Senator MITCHELL. Thank you, Dr. Willging. Mr. Halvorson?

[The prepared written statement of Dr. Willging follows:]

LONG TERM HEALTH CARE: AN OVERVIEW

by

Paul R. Willging, Ph.D.

Executive Vice President

American Health Care Association

I am Paul Willging, Executive Vice President of the American Health Care Association (AHCA), the largest association representing America's long term care providers. AHCA's membership exceeds 9,000 long term care facilities which care for about 900,000 nursing home patients each day.

I would like to take this opportunity to acknowledge and applaud the leadership of the Chairman and members of this committee for beginning to take a comprehensive look at long term care in this nation. The challenge of meeting the needs for long term care as our population ages is formidable, particularly the challenge of assuring access to quality care while containing public expenditures.

Of course, the most important factor affecting the need for long term care services is the growth in the elderly population. By the year 2000, over 13 percent of the population of American citizens will be over 65, while the number of elderly over 85 will have more than doubled. Today's 65-year old, for example, can expect to reach an average age of 81. Although advances in science and technology have been successful in prolonging life, however, they have not done as much to alleviate the disabilities associated with increasing age or the chronic effects of illnesses and traumas which in the past would have been terminal. Nursing home utilization among those age 85 and over is 14 times the rate of those 65-74. In short, this population is not only getting older, but "sicker" with more debilitating limitations.

Much attention has been given to improvements in the economic status of the elderly, in general. While this development is certainly good news and shows the potential for long term care insurance and other private financing arrangement, the improvement is far from uniform and many will be unable to afford long term care when they need it. In one recent study, approximately one-third of our elderly population would expend all their available resources and become Medicaid-eligible within 13 weeks after entering a nursing home. Two-thirds would exhaust their financial resources within the first year of a nursing home stay. Almost by definition, aging is associated with declining financial status due to depleting resources. Advancing age also means that a person is often left alone, outliving his or her spouse and families. When other family members exist they may not be available as caregivers, due to such factors as increasing employment among women and geographic mobility.

Clearly, as this vulnerable elderly population continues to grow, so will the need for nursing home care. Independent researchers have documented that an additional 1.2 million nursing homes will be needed by the year 2000 just to maintain the present age-specific level of service. In practical terms, a 220-bed nursing home would need to open each day through the year 2000 just to meet the projected demand for care. While the increased availability of noninstitutional services, such as home health care and community-based services, may to some degree reduce the total number of nursing home beds that will be needed, evidence suggests that their expansion may not have a significant impact on nursing home utilization. The recent National Long Term Care Channelling Demonstration project revealed that increased case management and formal community services did not significantly effect either hospital or nursing home use under its models.

In light of these demographic changes, AHCA believes that new and creative financing options for long term care services must be developed for the future. We must acknowledge that heavy financial burdens are placed upon individuals and their families in providing in-home care or financial support for institutional services. Thus, public policies must assure that nursing homes can continue to provide high quality long term care services, while assisting and encouraging individuals and their families to provide or help pay for such services in the future.

NEED FOR MEDICARE IMPROVEMENTS

The problem of patient access to Medicare skilled nursing facilities, the most intensive level of nursing home care, has become more critical. With the advent of the prospective payment system for hospital reimbursement, hospitals have incentives to transfer patients to skilled nursing facilities quicker and sicker. Indeed, with hospital discharges to skilled nursing facilities having increased by 40 percent in the past several years, the need to look at the entire continuum of care is essential.

Unfortunately, while Congress has focused its attention on the Medicare acute care area, it has sorely neglected the skilled nursing facility component which is now being pressured to provide follow-up services to these hospitals' newly discharged and often more acutely ill patients. Little has been done to the SNF benefit so that this component of the Medicare package can accomodate the predictable effects of changing hospital utilization.

This committee has recognized some aspects of the Medicare SNF access problems and related Medicaid nursing home issues by implementing some needed changes in the Consolidated Omnibus Budget Reconciliation Act (COBRA). Most significantly, COBRA provided a Medicare prospective payment for SNFs with a small number of Medicare patients, a moratorium on Administration efforts to eliminate Medicare's "waiver of liability" for providers that act in good faith to serve beneficiaries' post-hospital needs, and a modification of Medicaid's authority to recognize, at least partially, legitimate increases in property costs. I commend the members of this committee for your leadership to improve access and your continuing commitment to Medicare beneficiaries, and I look forward to working with you in the 100th Congress to identify further steps to ensure long term services for our elderly.

Despite public perceptions, Medicare provides scant coverage for nursing home services. Medicare covers only 100 days per spell of illness, is limited to persons who have had at least three days of hospital care and applies only to care in a skilled nursing facility. This small benefit is further diminished by Medicare's "fine print", notably restrictive medical eligibility criteria and excessive patient cost-sharing. As a result, Medicare paid only 1.9 percent of the nation's nursing home costs in 1984.

Need to Attract More SNF Participation

A primary barrier to Medicare patient access is the burdensome and inefficient reimbursement system for SNFs that acts to discourage facilities from choosing to participate in the Medicare program. Medicare pays for SNF services on a retrospective basis -- after the service is provided, a preliminary payment is made to the facility and a final payment is calculated approximately approximately one year later based on cost reports submitted by the facility.

In addition to significant delays in reimbursement, many low-level participators in the Medicare program are discouraged by the probability that they will not recieve full reimbursement for the higher costs of the Medicare patients that they serve. These low-level participators are not able to "distinct-part" the Medicare portion of their facilities, which results in skewed cost averaging that understates the true costs of care for Medicare patients.

As a consequence of this seriously flawed reimbursement system, less than 1/3 of the nursing homes have even sought Medicare certification to participate in the program, causing severe SNF bed shortages in many areas of the country. Medicare SNF access is so maldistributed that half of all patient days are provided by less than 500 facilites, out of over 16,000 nursing homes.

The General Accounting Office recently reported that 97 percent of hospital discharge planners are experiencing difficulty in placing Medicare patients in skilled nursing facilities. GAO cited Medicare rules and regulations as "the most important barrier" to patient access to post-hospital care. As a result, many Medicare beneficiaries in need of SNF services are unable to receive the appropriate care to which they are entitled, and often remain "backed-up" in expensive hospital settings longer than medically necessary awaiting SNF placement.

The Consolidated Omnibus Budget Reconciliation Act took a significant step in encouraging greater participation in Medicare by facilities providing less than 1,500 annual Medicare days of service. These facilities, as of October 1, 1986, have the option of accepting a prospective fixed per diem payment based on the SNF costs in the region, along with a substantially reduced cost report.

AHCA encourages the expeditious development and implementation of a prospective payment system for all SNFs under Medicare. With an appropriate prospective payment system, the Medicare program can achieve significant savings and enable beneficiaireis to recieve the appropriate services in the least costly setting. A prospective payment system would attract more provider participation in Medicare and respond to the increasing demand for Medicare SNF service resulting from hospital discharge incentives. This system is necessary to facilitate the continuity of post-hospital care and avoid hospital "back-up" crisis. As a mimimum, the current 1,500 Medicare day threshold for low-utilization SNFs should be raised to allow a greater number of facilities a prospective payment rate.

Need to Eliminate 3-day Hospitalization Requirement

Another barrier which should be eliminated is the requirement that to qualify for SNF services, beneficiaries must first spend at least three days in a hospital. This prior hospitalization requirement is arbitrary, unnecessary and burdensome. The removal of the requirement would recognize the legitimate needs of beneficiaries who require only skilled nursing services. It would also minimize the instances of unnecessary and costly hospital stays for patients trying to meet eligibility requirements for Medicare SNF benefits.

A provision in the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) gave the Secretary of HHS the authority to waive the three-day hospitalization requirement if such a waiver would not lead to an increase in costs. However, HHS has taken no action on the issue to date. In examining this issue, the Health Care Financing Administration conducted a three-year demonstration project which concluded that Medicare savings would result from elimination of the requirement. AHCA feels this change would provide Medicare beneficiaries greater flexibility for their long term care coverage and result in lowering costs for the patient, as well as the Medicare program.

At a minimum, the requirement should be eliminated when specific patient conditions can be identified for which the prior hospitalization requirement is neither cost-effective nor necessary to control inappropriate utilization. Examples of such situations include beneficiaries needing skilled nursing services for a terminal illness, patients recieving home health services who develop an intensified nursing need, or beneficiaries whose "spell of illness" has not ended because 60 days have not lapsed since the hospital or prior SNF care.

Need to Reduce Patient Cost-Sharing for SNF Care

Another priority issue which affects access to the Medicare SNF benefit is the burden cost-sharing presents to the Medicare patient. Currently, a $65 coinsurance payment is required of a SNF patient for each day of service from the 21st to the maximum 100th day of care. This coinsurance is so high that it exceeds the daily payment rate in most facilities so that, in effect, Medicare benefits cease in a SNF after 20 days. To use the full SNF "benefit" a Medicare beneficiary would have to pay $5,200, on top of the minimum prior hospitalization charge of $520.

This heavy patient cost-sharing for skilled nursing care is completely out of sync with the patient cost of other Medicare-covered services, such as the $520 hospital deductible for the first 60 days and the lack of any cost-sharing for home health services. In part, the high SNF coinsurance is an unfortunate result of being linked to 1/8 of the daily cost of hospital care, which has soared in the last several years under the prospective payment system for hospital reimbursement. AHCA strongly urges the committee to lower the SNF coinsurance rate by setting it at a percentage of the SNF payment rate rather than artificially linking it to hospital costs.

Need for a Prior Approval Mechanism

We commend the committee for its action to maintain the Medicare waiver of liability for SNFs and home health care agencies in the Consolidated Omnibus Budget Reconciliation Act. This waiver of liability provides protection for providers who act in good faith in accepting and providing services which may be found later by the intermediary not to warrant reimbursement. Providers are given a favorable presumption as long as their retroactive denial rate does not exceed five percent.

A growing number of retrospective denials of SNF claims, however, is creating hardship for Medicare beneficiaries and confusion among SNF providers. Increasingly, intermediaries across the country, with the implied consent of HCFA, are tightening eligibility standards in a capricious and arbitrary fashion which has severely constrained Medicare SNF caseload and caused regional inconsistencies. We have found that identical claims are approved in one office and denied in another office of the same intermediary.

We urge the comittee to take steps to ensure that eligibility criteria and standards are shared with Medicare beneficiairies and providers and that hearing officers are bound by Medicare regulations and the precedents established by conclusions of the appeals process. AHCA also believes that a prior authorization system is needed. Such a system would reduce costs incurred by beneficiaries during the claims review process and inform providers prior to or during provision of services as to Medicare eligibility, rather than after the fact.

NEED TO PRESERVE MEDICAID FUNDING FOR LONG TERM CARE

Medicaid continues to be the major source of public funding for long term care services. About 43 percent of nursing home costs are paid for by Medicaid, as compared with 1.7 percent covered by Medicare, less than one percent by private insurance and 50 percent by patients and families.

Many state Medicaid programs are driven by short-term budgetary concerns without any long-term or strategic planning objective. State reimbursement policies must be developed that result in reasonable financing arrangements that can effectively reduce program costs, emphasize quality of care for program beneficiaries and provide for rational growth in capital expenditure levels.

States should be encouraged to improve access of heavy care patients relative to that of light care patients by having the daily reimbursements recognize, and adequately pay for, the needs of individual patients. The recognition of patient need in daily reimbursements would encourage alternatives to institutionalization for light care patients and prevent the back-up of heavy care patients in hospitals. Research is currently underway to develop techniques for measuring the needs of Medicare patients and establishing an appropriate reimbursement based on case-mix, while several such Medicaid systems are currently operational.

States should also be given more flexibility to fashion their programs to the needs of their elderly populations, such as allowing states to purchase long term care insurance for their Medicaid population or allowing waivers of the "state-wideness" requirement which would allow states to target services to the most needy.

Need to Maintain Adequate Federal Funding

For the past three years, Congress has rejected the Administration's budget proposal to cap the Medicaid program and limit future growth by adjusting state payments by the medical price index. AHCA urges the Congress to reject the same recommendation to cap Medicaid when determining budget decisions for FY 1988. Additionally, AHCA opposes the Administration's proposal to eliminate the special matching rates for state administrative costs for survey and certification activities. In 1980, Congress cut the federal share of survey and certification costs from 100 to 75 percent. The committee should not further cut the federal share of these costs to 50 percent at a time when states are implementing the new patient care and services (PaCS) survey and attempting to upgrade the quality of inspectors.

Need to Remove Medicare Limit on Medicaid Reimbursement

HHS regulations limit the Medicaid reimbursement a state can pay to nursing homes and hospitals to an amount not greater than would have been paid if Medicare principles of reimburesement were used. Although this limitation may have served a purpose when Medicare reimbursement systems were all cost-based, that is not the situation now.

In 1980, states were given substantially more flexibility in designing their Medicaid nursing home reimbursement methods under Section 962 (the "Boren amendment") of the Omnibus Reconciliation Act. HCFA, however, has proposed regulations that would greatly limit the states' flexibility in Medicaid rate setting. HCFA wants to apply Medicare rate setting principles to Medicaid costs of small groups of facilities and is rejecting the contention that the Congressional intent was to compare Medicare rates statewide with Medicaid rates statewide.

Under the HCFA proposed regulation, states would be forced eventually to return to Medicare principles of cost reimbursement, thereby abandoning more innovative and efficient payment practices, such as prospective payment plans and incentives for serving patients with heavier care needs. We urge the committee to eliminate the application of such a limit as inappropriate and unworkable.

ENCOURAGING INDIVIDUAL AND FAMILY INVOLVEMENT

Fully one-half of long term care expenses in nursing homes are provided by personal resources of patients or their familes. To reduce government responsibility for financing long term care services, Congress should support policies which encourage personal savings for long term care needs and support the provision of informal caregiving by family and friends that will keep elderly individuals at home in the community.

Develop Respite Care Option Under Medicaid

Current Medicaid eligibility and benefit requirements encourage the permanent institutionalization of individuals and discourage family involvement in care of patients. Once institutionalized, many elderly quickly exhaust their financial resources paying for nursing home care and become financially dependent on Medicaid. Such individuals are rarely returned to the community after conversion to Medicaid, even if the person's condition improves, because of lack of personal financial resources and the general difficulty associated with readmitting a Medicaid patient to a nursing home.

In many cases, family members would be willing to care for their relatives, but require periodic and temporary repite from care-giving. Extended respite care could encourage families to continue sharing in the care of Medicaid or potential Medicaid recipients through a "block time" or time-sharing coincept which would provide limited duration nursing home care in lieu of permanent institutionalization. Block time would be periodic, but extended respite care would be designed to prolong the involvement of informal caregivers in the delivery of long term care services.

Encourage Personal Savings for Future Care Needs

One of the most significant advances in public policies affecting the ability of individuals to privately finance future long term care needs has been the extension of individual retirement accounts (IRA) eligibility to workers and their spouses. However, there are two major drawbacks in the IRA statutory requirements if this provision is to be considered a potential financial resource for paying for long term care services:

- no deduction is allowed individuals for contributions made after attaining age 70 1/2 and
- the individual must start drawing down on the IRA account upon reaching age 70 1/2.

These requirements fail to recognize the dynamics and demographics of the nursing home population. In fact, the mandatory IRA distribution age is many years before the typical nursing home admission at age 80. Forcing individuals to draw down upon IRA funds before these funds are necessary to pay for nursing home services is a self-defeating public policy. AHCA recommends that these two barriers be eliminated.

Encourage the Development of Private Long Term Care Insurance

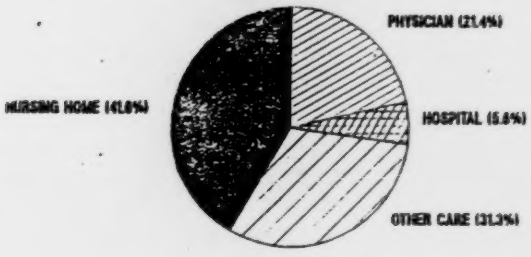
Up to one-quarter of projected Medicare outlays could be saved if more older Americans insured against the risk of nursing home and other long term care services, according to a study commissioned by the Department of Health and Human Services. The major obstacle to the development of private insurance, product design and financial viability have largely been overcome. The present and most formidable obstacle, is marketing, especially educating consumers about their vulnerability and overcoming psychological denial. Most Americans erroneously believe that Medicare will cover nursing home and long term care services and much must be done to educate the public as to limitations of Medicare and Medicap supplemental insurance policies. The federal government can also play a role as a marketing catalyst through tax incentives and other inducements encouraging individuals and employers to purchase long term care insurance.

Mr. Chairman, I would just like to commend you for your timely series of hearings on long term health care. Much remains to be done to adequately provide for the present and future long term care needs of our elderly, and I look forward to working with you to achieve progress toward that goal.

CHART 1

OUT OF POCKET HEALTH CARE EXPENDITURES FOR THE ELDERLY

BY TYPE OF SERVICE – 1984



TOTAL – 30.2 BILLION

CHART 2

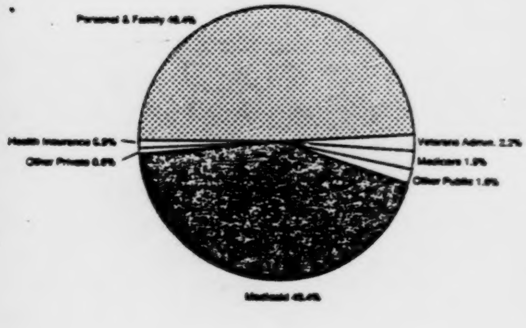
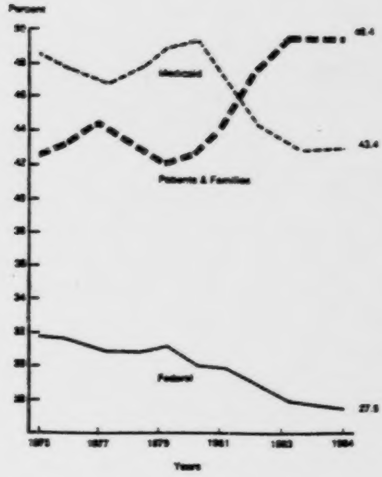


CHART 3



STATEMENT OF GEORGE HALVORSON, PRESIDENT, GROUP HEALTH, INC., MINNEAPOLIS, MINNESOTA; ON BEHALF OF THE GROUP HEALTH ASSOCIATION OF AMERICA

Mr. **Halvorson**. Good morning, Mr. Chairman. I am George Halvorson, President of Group Health, Inc., a Federally qualified, not-for-profit health maintenance organization. We are one of the largest HMOs in the midwest, with about 200,000 members. I am accompanied today by Leslie Rose, the Deputy Legislative Director for Group Health Association of America, GHAA, and I appear here today on behalf of GHAA, the National Trade Association for Organized Prepaid Health Systems. GHAA represents most of the HMO industry.

I have been asked this morning to talk about the NMO industry and long-term care. HMOs have a well-documented record of providing high quality, comprehensive health services through a delivery system that uses a case management approach and is geared to providing care in the most appropriate setting. HMOs do not generally cover long-term care in the form of custodial care in a nursing home.

Some HMOs, however, have become involved in innovative programs which include long-term care services and which may provide guidance to the subcommittee. One such program, referenced earlier, is the Social HMO, or SHMO, demonstration now taking place at four different sites around the country.

A Social HMO is a primary focus of my remarks this morning. Our SHMO, Seniors Plus, is a partnership with the Ebenezer Society, a well-respected organization in the long term care field. Three other organizations are participating in the Social HMO demonstrations: Kaiser Permanente in Portland, Elderplan of Brooklyn, New York, and SCAN Health Plan of Long Beach, California.

The idea behind the Social HMO is to provide a prepaid, integrated and efficient system for providing both traditional acute care and expanded care or long-term care services to Medicare beneficiaries. The SHMOs enroll Medicare beneficiaries on a voluntary basis, and more than 11,000 people are now enrolled at four sites.

The financing for the services comes from several different sources. Medicare pays 100 percent of the TEFRA Adjusted Average Per Capita Cost, or AAPCC. The AAPCC is the estimated cost of providing services to Medicare beneficiaries in the fee for service sector. For Medicaid eligibles, the State makes a payment to the Social HMO.

In addition, the beneficiaries pay a private premium plus some small and limited copayments for non-Medicare benefits. The premiums for the Social HMOs range from $25.00 to $49.00 per month, and that includes all acute care benefits, as well as long-term care.

One of the features of the Social HMO enrollment is that the case mix closely reflects the mix in the community in terms of sex, age, disability, and Medicaid eligibility. By balancing the population in terms of frail and healthy elderly, the SHMO attempts to enroll a cross section of the population in order to meaningfully test this concept for HCFA. The Social HMO benefits include a full set of acute medical care, as I mentioned, plus related services that are generally provided by an HMO, plus additional expanded long term care benefits.

Expanded benefits are provided for services not covered by Medicare with a per beneficiary maximum that ranges from $6,000 to $12,000 per year, depending on the site. Different limits on benefits and copayments apply also at each Social HMO. The range of services provided includes case management services, respite care, adult day care, personal care aids, and transportation. Short-term intermediate care facility services are also available.

The Social HMO does not cover custodial nursing home care. However, the sites do cover from two to four months of nursing home care beyond Medicare skilled care without any restriction on setting, condition or prior hospitalization.

How is the demonstration going? We have had some successes; we have identified some problems. All four sites have met their budgets for the costs of providing medical and long-term care services. One of the reasons for slower than projected enrollment has been marketing problems. The major marketing problem is what we call the "myth of Medicare." There is a common misconception among the elderly that Medicare or the current Medigap policies already cover long-term care.

We believe that all four of the HMOs participating in this program are testing concepts that are essential to the development of total health care programs for the elderly.

We are developing a new cost data base on long-term care that will be invaluable. Unfortunately, HCFA has shown some reluctance to continue our waivers, and that may well doom the approach as it is now constructed. Other HMOs are also offering expanded long-term care benefits, albeit on a lesser scale.

In 1982, under the Tax Equity and Fiscal Responsibility Act under TEFRA, a provision was enacted which permitted HMOs to become more meaningful participants in the Medicare program. According the the HCFA data, as of December 31, 1986 out of 144 TEFRA contracts involving approximately 900,000 enrollees, 78 HMOs—or more than half—now provide extended skilled nursing facility benefits as part of their basic Medicare package and four provide additional benefits under a high option plan. In some cases, the HMO benefit on skilled nursing facilities is extended; and in other cases, the HMO reduces or eliminates the copayments and deductible.

In addition to providing extended skilled nursing facility coverage, some HMOs with risk contracts have developed programs with local community groups, private organizations, and even State and local governments to provide additional long-term care benefits beyond the Medicare package.

I would mention that Group Health of Puget Sound, a sister plan to ours, is also involved in an innovative program with Metropolitan Life Insurance Company to offer a prepaid long-term care insurance plan in a case-managed setting. Basically, HMOs represent an alternative delivery system which has been accepted by a wide variety of individuals and groups, from Medicare, Medicaid, Federal, State, and local government employees to employees of large and small private companies.

Not every HMO has a Medicare contract, and not every HMO would like to offer a SHMO-like benefit. However, we hope that the information that is being gained from the Social HMO demonstration will be extremely to you.

[The prepared written statement of Mr. Halvorson follows:]

STATEMENT OF

GEORGE C. HALVORSON

Good morning Mr. Chairman and Members of the Subcommittee. I am George Halvorson, President of Group Health, Inc. a federally qualified non-profit health maintenance organization (HMO), which is one of the largest HMOs in the Midwest. I am accompanied today by Leslie Rose, Deputy Legislative Director for the Group Health Association of America, Inc. (GHAA, Inc.). I appear here today on behalf of GHAA which is the national trade association for organized prepaid health care systems and which represents most of the HMO industry.

I will summarize my remarks and request that my entire written testimony be included in the record.

I have been asked this morning to talk about the HMO industry and long-term care. HMOs have a well-documented record of providing high quality, comprehensive health services through a delivery system that uses a case management approach and is geared to providing care in the most appropriate setting. HMOs have been able to achieve substantial cost savings, in particular by significantly lowering unnecessary hospital utilization.

HMOs do not generally cover long-term care; i.e., custodial care in a nursing home. Some HMOs, however, have become involved in innovative programs which include long term care services and which may provide guidance to the subcommittee.

One such program is the Social HMO or SHMO demonstration now taking place at four different sites. The SHMO is the primary focus of my remarks this morning.

SOCIAL HMO DEMONSTRATIONS

Our SHMO, "Seniors Plus", is a partnership with the Ebenezer Society, an honored organization in the long term care field. Three other organizations are participating in the SHMO demonstration: Kaiser Permanente Portland; Elderplan of Brooklyn, New York and SCAN Health Plan of Long Beach, California.

The idea behind the SHMO is to provide a prepaid, integrated and efficient system for providing acute and expanded care or long term care services to Medicare beneficiaries.

The SHMOs enroll Medicare beneficiaries on a voluntary basis and more than 11,000 people are presently enrolled at the four sites. The financing for the services come from several different sources. Medicare pays 100 percent of the TEFRA Adjusted Average Per Capita Cost or AAPCC, which is the cost of providing services to Medicare beneficiaries in the fee for service sector; for Medicaid eligibles, the state makes a payment to the SHMO. In addition, a private premium, plus any copayments, is paid by the beneficiary. The premiums currently range from $25 to $49 per month.

One of the features of SHMO enrollment is that the case mix closely reflect the mix in the community in terms of age, sex, disability and Medicaid eligibility. By balancing the population in terms of frail and healthy elderly, the SHMO attempts to minimize financial risk while meaningfully testing this concept to HCFA by not having favorable selection.

The SHMO benefits include acute medical care, plus related services as generally provided by an HMO, plus additional "expanded care" (EC) benefits. These latter benefits are provided for the cost of services up to $6,000 - $12,000 per year. Different limits on benefits and copayments apply. The range of services provided include case management services, respite, adult day care, personal care aid and transportation. Short term intermediate care facility (ICF) services are also available.

The SHMO does not cover custodial nursing home care. However, the sites do cover from two to four months of nursing home care beyond Medicare skilled care without any restriction on setting, condition or prior hospitalization.

How is the demonstration going? We have had some successes and identified some problems. Our plan and Kaiser have each reached their financial "breakeven" points. SCAN and Elderplan project hitting breakeven by the start of the third year of the demonstration. All four sites have met their budgets for the costs of providing medical and long term care services.

One of the reasons for slower than projected enrollment has been marketing problems. One of which is the general perception among the elderly that Medicare covers long term care. We believe that all four of the HMOs participating in this program are testing concepts essential to the development of total health care programs for our elderly, including a new cost database on long term care services. Unfortunately, HCFA has shown some reluctance to continue our waivers.

MEDICARE RISK CONTRACTS

In 1982, under the Tax Equity and Fiscal Responsibility Act (TEFRA), a provision was enacted which permitted HMOs to become more meaningful participants in the Medicare program. TEFRA created a prospective reimbursement system which was more consistent with the HMO delivery system. Under a TEFRA contract, the HMO must provide at a minimum, all Medicare covered Part A and Part B services.

According to HCFA data as of 12/31/86, of 145 TEFRA contracts, with approximately 900,000 enrollees, 78 HMOs and competitive medical plans (CMPs) provide extended SNF benefits as part of their basic Medicare package and four (4) provide it under a high option benefit. In some cases, the limit on SNF days is extended. In some cases the HMO premium reduces or eliminates the copayments and deductible.

In addition to providing extended SNF coverage, some HMOs with risk contracts have developed programs with local community groups, private organizations and even state and local government, to provide additional services beyond the basic Medicare package. Although we have no industry data in this area because these services are often provided on a case by case basis, we can offer an example which is representative. In the state of Washington, the Group Health Cooperative of Puget Sound developed a volunteer program which aids the elderly and others who are recovering from a spell of illness. Volunteers provide respite care, meal preparation, shopping, light housework and transportation to medical appointments. These types of benefits are maybe provided or arranged by the HMO, according to our discussions with our member organizations.

At the same time, a recent GHAA survey of the HMO industry showed that in 1985, only 2.5 percent of HMOs did not offer a home health benefit. Over seventy percent offered this benefit without limits or copayments.

LONG-TERM CARE INSURANCE

One other innovation worth mentioning is the long-term care insurance proposal developed by Group Health Cooperative of Puget Sound and the Metropolitan Life Insurance Company. Beginning March 15, Medicare enrollees of Group Health will be able to purchase this coverage. There will be two different benefit packages - both will offer custodial care; the more comprehensive and expensive package will offer home care. This product allows the life insurance company to use its financial resources and underwriting experience in partnership with the HMO which has the ability to manage the care and control costs. At this time, this is the only program of its kind and it is uncertain how many people will take advantage of this program. There is an incentive to sign up early - the younger the person who signs up, the lower the premium throughout their enrollment with the program.

CONCLUSION

HMOs represent an alternative delivery system which has been accepted by a wide variety of individuals and groups, from Medicare, Medicaid, federal, state and local government employees to employees of large and small private companies. Not every HMO has a Medicare risk contract and not every HMO would want to offer a SHMO - like benefit. However, we hope that the information and experience gained from some of the programs highlighted today, as well as the managed care approach which is central to our industry, may help all of us to address the very serious problem of providing adequate long-term care services to the elderly.

I'd be happy to answer any questions.

STATEMENT FOR THE RECORD OF
GEORGE C. HALVORSON

PRESIDENT
GROUP HEALTH, INC.

ON BEHALF
OF THE

GROUP HEALTH ASSOCIATION OF AMERICA, INC.

ON
LONG TERM CARE SERVICES

BEFORE THE

SUBCOMMITTEE ON HEALTH
SENATE FINANCE COMMITTEE

FEBRUARY 24, 1987

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One of the features of SHMO enrollment is that the case mix closely reflect the mix in the community in terms of age, sex, disability and Medicaid eligibility. By balancing the population in terms of frail and healthy elderly, the SHMO attempts to minimize financial risk while meaningfully testing this concept to HCFA by not having favorable selection.

The SHMO benefits include acute medical care, plus related services as generally provided by an HMO, plus additional "expanded care" (EC) benefits. These latter benefits are provided for the cost of services up to $6,000 - $12,000 per year. Different limits on benefits and copayments apply. The range of services provided include case management services, respite, adult day care, personal care aid and transportation. Short term intermediate care facility (ICF) services are also available.

The SHMO does not cover custodial nursing home care. However, the sites do cover from two to four months of nursing home care beyond Medicare skilled care without any restriction on setting, condition or prior hospitalization.

How is the demonstration going? We have had some successes and identified some problems. Our plan and Kaiser have each reached their financial "breakeven" points. SCAN and Elderplan project hitting breakeven by the start of the third year of the demonstration.

All four sites have met their budgets for the costs of providing medical and long term care services. However, except for

Kaiser, overall costs have exceeded revenues. There have been higher costs than anticipated for marketing. In fact, one of the reasons for slower than projected enrollment has been marketing problems. One of which is the general perception among the elderly that Medicare covers long term care. In addition, both Elderplan and SCAN have had higher administrative and overhead costs, having created brand new HMOs for this demonstration.

We believe that all four of the HMOs participating in this program are testing concepts essential to the development of total health care programs for our elderly, including a new cost database on long term care services. Unfortunately, HCFA has shown some reluctance to continue our waivers.

MEDICARE RISK CONTRACTS

In 1982, under the Tax Equity and Fiscal Responsibility Act (TEFRA), a provision was enacted which permitted HMOs to become more meaningful participants in the Medicare program. TEFRA created a prospective reimbursement system which was more consistent with the HMO delivery system. Under a TEFRA contract, the HMO must provide at a minimum, all Medicare covered Part A and Part B services.

The HMO usually charges a premium, sometimes copayments, and often provides supplemental benefits beyond the basic Medicare covered services and uses any excess income for the provision of additional services. For example, according to HCFA data as of

12/31/86, of 145 TEFRA contracts, with approximately 900,000 enrollees, 78 HMOs and competitive medical plans (CMPs) provide extended SNF benefits as part of their basic Medicare package and four (4) provide it under a high option benefit. In some cases, the limit on SNF days is extended, in some cases the HMO premium reduces or eliminates the copayments and deductible.

In addition to providing extended SNF coverage, some HMOs with risk contracts have developed programs or made agreements with local community groups, private organizations and even state and local government, to provide additional services beyond the basic Medicare package. Although we have no industry data in this area because these services are often provided on a case by case basis, we can offer an example which is representative. In the state of Washington, the Group Health Cooperative of Puget Sound developed a volunteer program which aids the elderly and others who are recovering from a spell of illness. Volunteers provide respite care, meal preparation, shopping, light housework and transportation to medical appointments. These types of benefits are often provided or arranged by the HMO, according to our discussions with our member organizations.

At the same time, a recent GHAA survey of the HMO industry showed that in 1985, only two and one half percent of HMOs did not offer a home health benefit. Over seventy percent offered this benefit without limits or copayments.

Preliminary survey results of GHAA member organizations have shown that of those HMOs offering a Medicare supplemental package, 31.6 percent state that the benefits currently include additional benefits for nursing home or other long-term care benefits. Again, our initial information is that these benefits are primarily SNF, home health and hospice coverage. 6.6 percent of our respondents said they were considering offering such benefits.

The survey also revealed that 32.9 percent of our members offer some type of long-term care benefit to their non-Medicare enrollees as part of their regular benefit package and 17.1 percent are considering such coverage. These benefits also appear to be primarily skilled nursing care and home health care.

Finally, when asked whether the organization offered a rider for long-term care coverage, that is, a supplemental benefit for an additional premium, preliminary results are that 6.6 percent of our members do offer such a rider and 6.6 percent are considering such coverage.

LONG-TERM CARE INSURANCE

One other innovation worth mentioning is the long-term care insurance proposal developed by Group Health Cooperative of Puget

Sound and the Metropolitan Life Insurance Company. Beginning March 15, Medicare enrollees of Group Health will be able to purchase this coverage. There will be two different benefit packages - both will offer custodial care. In addition, the more comprehensive and expensive package will offer home care. The new offering allows the life insurance company to use its financial resources and underwriting experience in partnership with the HMO which has the ability to manage the care and control costs. At this time, this is the only program of its kind and it is uncertain how many people will take advantage of this program. There is an incentive to sign up early - the younger the person who signs up, the lower the premium throughout their enrollment with the program.

CONCLUSION

HMOs represent an alternative delivery system which has been accepted by a wide variety of individuals and groups, from Medicare, Medicaid, federal, state and local government employees to employees of large and small private companies. Not every HMO has a Medicare risk contract and not every HMO would want to offer a SHMO - like benefit. However, we hope that the information and experience gained from some of the programs highlighted today, as well as the managed care approach which is central to our industry, may help all of us to address the very serious problem of providing adequate long-term care services to the elderly.

I'd be happy to answer any questions.

Senator MITCHELL. Did you say that those Social HMO contracts do not provide for long-term care?

Mr. HALVORSON. No, they do provide long-term care.

Senator MITCHELL. They do?

Mr. HALVORSON. They provide extensive long-term care with a focus on in-home care. Relative to nursing home care, the benefit limits varies from $6,000 to $12,000 per site.

Senator MITCHELL. If extended nursing home care is required, it may not be covered?

Mr. HALVORSON. If there is extensive nursing home care, it may not be covered. However, the alternative is to keep people in the homes; and there is extensive coverage for home health, health aids, transportation, respite care, caregiver care—that type of thing.

Senator MITCHELL. They will provide part of the answer, but there will still be a gap there?

Mr. HALVORSON. Yes. There is still a gap there.

Senator MITCHELL. Let me start with you, Mr. Halamandaris, and then I will ask the others to answer. You commented on the British system.

Mr. HALAMANDARIS. Yes, sir.

Senator MITCHELL. We are going to have a separate hearing later on financing, but obviously, that is the central issue. You have all very eloquently described the problem. Do you believe that we should expand Medicare to cover long term care; and if so, how do you propose that it be paid for?

Mr. HALAMANDARIS. Mr. Chairman, the short answer is yes. However, I would like to back up one space and say that I don't think we are making very good use of the money we now spend. The Medicaid program, for the most part, is an institutional program. The Nursing Home Without Walls program in New York State is one which recaptures a lot of that money and takes care of more people in home care and prevents or postpones the need for institutional placement.

If I were going to do one thing as counsel to this committe, I would recommend that every State be required to have the equivalent of a Nursing Home Without Walls program. Let's see if we can keep people out of nursing homes and make greater use of less expensive services. That makes a lot of sense.

Secondly, I think the program that we are dealing with is so massive that we have no choice really but to bring in the combination of different funding sources. General revenues will be needed. I also think the States have to contribute. But I think we have to find ways of getting individuals to pay some of the premium, and I think a mandatory insurance program is the only way we can go because the problems of the elderly are an adverse selection. I think you went into all of that with the previous witnesses.

I do think that senior citizens will pay a lot more than $5.00 a month if you can guarantee them some meaningful long-term care coverage. We saw that in our investigation of the abuses in the sale of Medigap policies. Here are these senior citizens buying one, two, three, four, five, and sometimes as many as ten policies in a vain effort to try to cover themselves for long-term care.

They were spending $1,000—some of them—a month in order to try to get coverage. So, I think if we were to provide a policy for a premium of $50.00 a month, it would be quite reasonable, I think, to expect senior citizens to spend $600.00 a year for some real protection as opposed to $5.00 a month for something less than protection.

Senator **Mitchell**. I would like to ask the others to respond to the question.

Mr. **Goldberg**. You asked probably the knottiest question of all: How do you pay for all this care which we are advocating? I would like to maybe draw back to some parallels. I am not so sure today we have the economic resources to do all things for all people; and yet, there is a partnership, I think, that is mandated in this area, both in terms of what the Federal Government and the State governments can do, but also what the private insurers can do.

I think what we might try as a good first step is to stimulate the environment where the private insurance industry can flourish, where there is a market for it. We heard from the HMOs. The biggest problem is that many of the elderly people assume that they are covered by Medicare and, in fact, they are not. A study by AARP about two years ago found that 80 percent of the elderly thought that Medicare covered their nursing homes when, in fact, it doesn't. It is minimal if anything whatsoever.

So, I think we have to create an environment where the elderly know—and education is probably the most important aspect—and that is the leadership you have taken today, of conveying to the elderly that there is a risk out there. And hopefully, it is stimulating some private markets on a number of other issues. One other issue I would like to draw you to. There is a system that has been in place for many, many years, providing long-term care insurance, and that is a concept called Life Care.

It is primarily a not-for-profit entity. Many of them have been in existence for 25, 30, or 40 years, where a person literally creates through an endowment or an entry fee or an accommodation fee a pool—a risk pool. And literally, the person is guaranteed, generally through a contract, that they will be cared for independence, whether home health care is needed, whether total custodial care, such as through a nursing home, is covered.

I would draw one interesting to the elderly in this country. A study done by the Wharton School of Finance with the University of Pennsylvania in 1982 came up with some conclusions. There were suggestions from this study. Those who enroll in the Life Care, number one—generally, there is three years longer longevity. Number two, as best we can measure quality of life, it was enhanced significantly. These were happy people. And three—which should be very important to the financing of this program—is that there was significant reduction in Medicare expenditures, which is a direct financial obligation of the Federal Government.

So, I think there is a model worth looking at in the Life Care. It is not the answer for all, but it is one of the models, such as Social Health Maintenance Organizations, Homes Without Walls, and a number of other programs that move in this direction.

Senator **Mitchell**. Thank you. Dr. Willging.

Dr. WILLGING. I would generally agree with my colleagues, Mr. Chairman. I disagree perhaps ever so slightly with Mr. Halamandaris. I don't think there is that much more money to be eked out of the system in terms of alternatives to nursing home care. Home care is a critical part of the continuum, no question about it. The Nursing Home Without Walls program in New York is exemplary and should be lauded. But as you will note, as you look at the average age of people in the Nursing Home Without Walls program in New York, it is much less than the average age of nursing home residents in the State of New York. There does come a point on the long-term care continuum where the institution is the only viable alterative; but in terms of long-term financing, yes, I think insurance today is the most viable, as yet not really tested, option available to us.

Senator MITCHELL. Private insurance?

Dr. WILLGING. Private insurance. I tend to agree with Mr. Halamandaris that we may, as a society, at some point down the pike have to come to grips with the issue as to whether it needs to be mandated through some form. But what I would suggest in the short run—again referring to Governor Bowen's proposals—there are a number of mechanisms he has suggested to at least let us try to stimulate the growth of that phenomenon. Let's at least try those. At some point, we may have to go one step further; but let's start with that first step along what could be a very lengthy but still a very beneficial road.

Senator MITCHELL. Mr. Halvorson?

Mr. HALVORSON. I would say that an extension of Medicare to cover long-term care does make sense, with a focus on noninstitutional benefits and that the way that it could be paid for would be through a public/private partnership, possibly income-based premiums with a mandatory insurance program and extensive flexibility relative to involving management care systems in the delivery system. I think that would be the most efficient and highest quality way of delivering that care.

Senator MITCHELL. You raised a point that I will get to later, but first, Mr. Halamandaris, do you think a sufficient data base exists to calculate what a monthly premium should be? Let's assume we wanted to create a Medicare, Part C to cover all catastrophic expense. Dr. Bowen is using existing data calculating a precise amount for acute care. Do you think it would be possible, given the current body of knowledge to calculate such a figure that would embrace all catastrophic circumstances?

Mr. HALAMANDARIS. Mr. Chairman, I think that data is a bottomless pit. You are never going to have enough data. You are never going to have all the data that you need and I need to make precise decisions. I think we have to recognize that we have to make the best of the data that we have and, to some extent, we are guessing; and we have to adjust the program as we go. I do think we have enough data to make a responsible decision as legislators. Yes.

Senator MITCHELL. Was the $50.00 a purely hypothetical figure that you used, or were you approximating something you think it would actually turn out to be close to?

Mr. HALAMANDARIS. Mr. Chairman, I have tended to follow Congressman Claude Pepper pretty carefully. He has been right more times than he has been wrong. And his legislation, I think, suggests that figure, and I don't know exactly how it is calculated; but that is what I was reflecting.

Senator Mitchell. Mr. Halvorson referred to income relation in his response. What do you gentlemen think of relating Medicare benefits generally to income and, more narrowly, to the cost of some catastrophic care? One of the problems I have with Dr. Bowen's proposal, for example, is that it is defined as a catastrophe to have $2,000 in out-of-pocket medical expenses. That may be, in fact, a catastrophe for most Americans; but for someone who has an income of $1 million a year, it is absurd to suggest that that is a catastrophe. It is an inconvenience perhaps; it is a big medical bill; but it surely is not a catastrophe.

The biggest problem in this area—as this whole morning of testimony has demonstrated—the difficulty of coming up with the resources—does it make any sense finally to relate benefits under Medicare to income, at least in the area of catastrophic illness?

Dr. Willging. I was privileged, Mr. Chairman, to sit on the Secretary's Private/Public Sector Task Force on the issue of catastrophic health care expense. And while it did not surface in the Secretary's ultimate proposal to the President, there was strong concensus—indeed all but unanimity—on that task force that indeed the catastrophe had to be related in some form to the actual income available to the individual. For most, if not the vast majority of America's elderly, $2,000 might indeed be a catastrophic expense. For others, and a large minority of the elderly population, it would not. And at some point, we do have to recognize that the benefits should be tied to the individual's ability to finance those out of his or her own pocket.

Senator Mitchell. Mr. Halamandaris, do you have a comment on that?

Mr. Halamandaris. That is the toughest question you could ask, Mr. Chairman. I think that it would be destructive on balance because it would destroy the existing contract between the senior citizens of this country and the Medicare program. They now look at the Medicare program as a right, something they had worked for in their earlier years, in order that they might benefit when they are older. They would be looking at the Medicaid program, by contrast, as a handout. I think if we were to means test the long-term care part of the Medicare program, it would tend to make it viewed by the elderly as a handout, something which is——

Senator Mitchell. Do they regard Social Security retirement as a handout?

Mr. Halamandaris. I think Social Security retirement they view again as a vested right, something again they have worked for.

Senator Mitchell. Is it not true that the benefits of Social Security are related to income, the replacement ratio——

Mr. Halamandaris. In that sense, yes.

Senator Mitchell. Is it also not true that Social Security retirement income is subject to tax, once income goes over a certain level?

Mr. Halamandaris. That is true.

Senator Mitchell. And so, notwithstanding the fact that Social Security retirement is clearly income related, and has been since its inception, and is now increasingly so with the imposition of a tax above a certain level, it is fair to conclude—is it not?—that the elderly do not regard it as a handout?

Mr. **Halamandaris.** I think, Mr. Chairman, I could agree with your analysis, but I was projecting my particular prejudices on this point.

Senator **Mitchell.** Yes. Well, I have the same concern. The reason the Social Security—the entire system—enjoys such broad public support in this country is in part because it is not viewed as a welfare program. But you encounter the circumstance here with Medicare and it is brought into focus with long-term care; that is, can we afford as a society to continue to provide benefits to persons, without regard to income, if the result is to deny services to many who need them? That is the cruel dilemma which we face. If we refuse to relate catastrophic benefits under Medicare to income, then we guarantee that there will be no program— politically acceptable in our society—that meets the needs of those who most need help. And it is a very difficult choice. I don't want to suggest by my questions that I have made a decision on it; but I find increasingly that we have to answer that difficult problem.

Mr. **Halamandaris.** That is true.

Senator **Mitchell.** And we have to acknowledge that if we say "no" to income relating, then we are saying "yes," we are going to provide benefits to some people who don't need them and deny benefits to some who do.

Mr. **Halamandaris.** True.

Dr. **Willging.** Mr. Chairman, I think there is a way of combining both your concerns and those of Mr. Halamandaris. If for example, taking the approach of a mandated long-term care insurance program, the way that the more affluent elderly would deal with their fair share and then some, given their income, would be that, of course, above a certain income level, they are responsible for the entire premium for that policy. A program such as Medicaid—an expanded Medicaid program in this area—would on a sliding scale take care of the premiums for those who in fact do not have the wherewithal. So, I think one can maintain the integrity of the program as a nonwelfare program, but at the same time recognize the fact that different individuals have different resources and may have to contribute more.

Senator **Mitchell.** That is one of the things I was thinking about—sliding scale deductibles and premiums. Mr. Goldberg?

Mr. **Goldberg.** I just wanted to say that there is still room in this country for some individual responsibility. Such things as the IRAs, but what we are now talking about as the individual medical accounts—I would not want to take anything away that takes away individuals' responsibility to plan for themselves. And I don't want to come back and hit the issue of education, but that is crucially important.

There is another issue that is one of equity, that I would like to at least bring up to this committee. We have an issue called divestment. And I hear from people who run homes—nursing homes—around the country where individuals who come with very significant affluence—a lot of money—and on one day they may come up with very significant assets, and the next day they are now on the poverty program called Medicaid by simply in very interesting ways divesting themselves of economic resources; and all of a sudden, they are poor—whether they have given it to the kids or whomever, but generally the kids, or someone like that.

I think that is one of the areas, when we start talking about means testing a program and saying we are opposed to this thing, and yet we still have a situation in this country where we allow for individuals with significant assets to divest themselves and literally we turn our backs on those and allow them to go on Medicaid—then I think we have an equity question here. I think that people have to be individually responsible to their best; and there is a very significant role for Government here, but obviously, if divestment is there, how do we try to create this means testing for Medicare?

Senator MITCHELL. Of course, the problems with the IMAs is the same problem as with the IRAs. The IRAs, of course, were wildly popular in this country, and yet the majority of American families earn less than $30,000 a year; and those families with incomes of less than $30,000 a year, fewer than 10 percent of them had IRAs. The IRA participation rises very sharply with income and was and is principally a mechanism used by persons in, I would say, upper middle income and higher income brackets.

If you would have fewer than 10 percent of families earning less than $30,000 a year participating in IRAs, that tells you that they don't have money to set aside for these purposes. And that is precisely the problem you arrive at with respect to these enormous medical costs. It obviously would be desirable to encourage people to set aside money for this purpose. The reality of life for most people in those income brackets is that they simply don't have the money to set aside for that purpose. So, what you would be doing with IMAs is exactly what you did with IRAs. You would be encouraging those who are most able to do so to set aside the means.

And I don't mean that is undesirable, but it doesn't get at the core problem.

Mr. HALVORSON. Mr. Chairman, I mentioned the issue of income means testing, and I agree that it would be a betrayal of the trust that the senior citizens have in the Medicare system if the current benefits were means tested. I was suggesting that for additional benefits, for extension to catastrophic benefits, that the appropriate way of dealing with that would be to have some form of a mandated program whose premium would be means tested and made available through the private marketplace. And relative to the issue of divestiture, I think people would be much less likely to divest themselves of their assets if the only result of that would be to have a lower insurance premium. I think that they are likely to do that if the result is they can avoid catastrophic nursing home bills; but if the difference is between paying $80.00 a month or $20.00 a month in a premium, they are not very likely to move assets to their children to save that small amount of money.

I should also mention that the comments I just made are my own and not GHAA's.

Senator MITCHELL. Right. I understand that. Thank you. You see, you raise a troubling question, though. Believe me, I don't like to advocate means or income testing; and I don't know that I ultimately will support that, but currently, benefits under Medicare are provided to all participants regardless of the length of time that they contributed to the trust fund.

That is correct, isn't it?

Mr. Halvorson. Yes.

Senator Mitchell. Now, that is not the case with Social Security retirement. And indeed, we have fought in this committee over the past years on this whole question of public employees who, on leaving public employment, other than Federal employment, worked the minimum quarters necessary to qualify for Medicare. They get exactly the same benefits as the person who has worked for 50 years and contributed to Social Security or contributed to the Hospital Trust Fund since its inception.

Now, does that make sense? Is that fair? Is that something to be perpetuated? Particularly when one of the products of it is—I emphasize—one of the products of it is you are unable to devise a system that meets the legitimate health care needs of people who cannot otherwise meet them. You see, in the abstract, to say are you for income testing or not for income testing, that is an easy choice. No. Because you ensure broader public support by not making it income tested. That is easy. But when you ask the question the other way: Do you still reject income testing even if it means that to do so results in a circumstance in which elderly Americans who need long-term care cannot receive it? Then you are confronted with a much more difficult question.

That, I think, is the question on which this whole debate will turn: Whether we can devise a mechanism for dealing with this very serious problem of long-term care. I will give you the last word, Mr. Goldberg.

Mr. Goldberg. Dr. Brody made a comment earlier, and I guess I would reflect my own comments here; but Dr. Brody talked about this changing demographics in this country. It is an imperative facing this country. You know, the numbers of those in the work force—as those Yuppies grow older—and as a whole bunch of us grow older—the number of people, because of zero population, those contributing to trust funds, you are raising a very difficulty and very knotty problem which could create a whole series of intergenerational problems in this country. How do we allocate these scarce resources? We don't have the solution, except we are dealing with this issue now so we are not going to be dealing in a catastrophic environment in the fmture in trying to provide these programs.

Senator Mitchell. Of course, you have made a point that requires even further caution in approaching the problem. Nobody wants to say—and Mr. Halamandaris very diplomatically mentioned the British system—but nobody wants to say, of course, that we need to impose a new broad-based tax to support this expenditure because it would be very difficult to gain public acceptance and therefore political acceptance for it in our society. Even if we were to do that, we have to recognize that demographically this is an optimum time to do that, with the baby boom generation reaching its prime earning years and the ratio of retirees to workers being lower than it will be in the next 50 years.

Any system created now would have to take into account the dramatic changes that will occur in the first quarter of the next century. And that makes a very difficult problem even more difficult.

Gentlemen, I thank you all very much for your very informative testimony, and we look forward to working with all of you on this problem. The hearing is adjourned.

[Whereupon, at 12:25 p.m., the hearing was recessed.]

[By direction of the chairman the following communications were made a part of the hearing record:]

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STATEMENT
OF THE AMERICAN HOSPITAL ASSOCIATION
ON LONG-TERM CARE

Submitted to the
SUBCOMMITTEE ON HEALTH
U.S. SENATE COMMITTEE ON FINANCE

March 12, 1987

SUMMARY

Three misperceptions tend to dominate thinking about long-term care:

- That long-term care is exclusively a problem for the elderly. Although age is an important determinant, long-term care needs are a function of both physical and psychological disabilities that impair daily functioning at any age.
- That long-term care is equivalent to nursing home care. Most long-term care (70 percent) is provided at home and in the community, not in nursing homes, and entails not only skilled care but also assistance in the activities of daily living.
- That long-term care is paid primarily by public funds through Medicare and Medicaid. Nearly half of all nursing home costs, which account for almost one-third of long term care costs, are paid out-of-pocket by recipients or their families. Most of the public funding for nursing home services comes from Medicaid, which pays for about 45 percent of nursing home expenses.

Long-term care has become a pressing public policy problem because the costs associated with long-term care are enormous, the need for long-term care is likely to grow, and current reliance on the Medicaid program for long-term care for the elderly is straining that program's ability to provide acute services for the poor.

In the short term, the American Hospital Association (AHA) recommends closing the gaps in Medicare coverage to make extended-care services more accessible to beneficiaries. Specifically, Congress should:

- Require that the coverage criteria used by Medicare fiscal intermediaries be written and available to beneficiaries and providers;
- Relax the intermittent and home bound requirements for home health coverage and the conditions for waiver of the prior hospitalization rule for access to extended care services in skilled nursing facilities;
- Provide community based waivers under Medicare to experiment with the provision of non-hospital services, including social services, in case-managed programs using community services;
- Where post-hospital extended-care services are not available, allow hospitals to furnish services and be paid at the appropriate rate;
- Detach the Skilled Nursing Facility (SNF) copayment from the hospital inpatient deductible so that Medicare pays a fair share for covered skilled nursing stays;
- Eliminate the 190-day limit for inpatient psychiatric hospital services; and
- Conduct a study on potential modification of the 2-year waiting period for disability coverage for the permanently disabled.

In addition, the AHA recommends as an alternative to the "spend down" requirements for Medicaid eligibility a system of federal and state loans, guaranteed by an individual's estate, to allow spouses or dependents of individuals in nursing homes to qualify for public assistance by pledging a percentage of their assets. The spouse or dependent would continue to enjoy the use of property and investment income until he died or decided to liquidate the estate.

In the long term, AHA recommends a system combined of private and public funding that encourages individuals to provide for their own long-term care as much as possible, and provides access to needed long-term care when individual resources are inadequate. Such a program should be flexible in financing to encourage innovations in delivery, including case management to assure continuity of care.

In recognition of the fact that Medicaid has become a program of supplemental long-term care insurance for the elderly, the AHA recommends restructuring the Medicaid program into three distinct parts:

- A program of acute care coverage for the poor;
- A program to purchase supplemental acute coverage for the low-income elderly and disabled under Medicare Part B; and
- A program of long-term care insurance, funded by either the states or a combination of state and federal appropriations.

INTRODUCTION

The American Hospital Association, on behalf of its 5,600 institutional and over 40,000 personal members, welcomes this opportunity to submit comments on the issue of long-term care. The AHA commends the committee for addressing this critical issue. With all the attention now placed on protections for catastrophic acute care, it is particularly important to consider the catastrophic needs of the chronically ill and disabled.

THE NATURE OF LONG-TERM CARE

It is important when thinking about long-term care to overcome three common misperceptions.

Long-term care is not exclusively a problem for the elderly. Although age is an important determinant, long-term care is a function of both physical and psychological disabilities that impair daily functioning, so the population at risk for catastrophic long-term care expenses includes both the elderly and non-elderly chronically sick and disabled, as well as the developmentally disabled and chronically mentally ill.

Long-term care is not equivalent to nursing home care. Although our public policies have tended to focus funding and delivery of long-term care on inpatient institutional care, 70 percent of all long-term care is provided at home or in the community and entails not only skilled care but also assistance in the activities of daily living--personal and social services like assistance with eating, walking, or bathing, as well as shopping, meal preparation, and housekeeping. Because long-term care is by definition a response to social and psychological needs, any attempt to address long-term care without accomodating the need for social and psychological services would be sorely deficient. The availability of these non-medical services often can mean the difference between maintenance in the community and much costlier institutionalization.

Only a small proportion of long-term care is paid by public funds. As noted above, most long-term care is non-institutional, while public programs have focused their financing on the provision of nursing home care. Furthermore, nearly half of nursing home costs are paid out-of-pocket by recipients or their families. Most of the public funding for institutional long-term care services comes from Medicaid, which pays for about 45 percent of nursing home expenses. Medicare's acute care orientation has rendered it a limited factor in the provision of long-term care. Medicare pays for less than 2 percent of nursing home costs and nothing for such long-term care services as adult day care, emergency response, homemaker services, or special services required for Alzheimer's disease patients.

Hospitals have increasingly become involved in the provision of long-term care services. In 1986, 40 percent of community hospitals provided extended care through hospital-owned or -operated skilled nursing facilities, swing beds, intermediate care facilities, or psychiatric long-term care facilities. Understandably, the most rapid growth in recent years has been in the development of skilled nursing facilities and home health services, the more intensive and medically oriented long-term care services. Between 1983 and

1985, the percentage of community hospitals owning home heatlh agencies doubled, from 15.5 percent to 33.3 percent; hospital ownership of SNFs grew during that time by 50 percent, from 15.4 percent to 22.6 percent. But hospitals also provide, in increasing amounts, day hospital care, rehabilitation, adult day care, and hospice services.

THE PROBLEM OF LONG-TERM CARE

Long-term care has become a pressing public policy problem because the costs associated with long-term care are enormous, the need for long-term care is likely to grow, and current reliance on the Medicaid program for long-term care for the elderly is straining its ability to provide acute services for the poor.

Long-term care is the leading cause of catastrophic health care expense. Nearly half of all institutional long-term care expenses are privately paid, accounting for slightly over 40 percent of all personal expenditures for health care. Medicare provides only limited coverage for post-acute skilled nursing care, and no coverage for intermediate care or custodial home health care. As a result, almost half of the 75-year-olds who enter private nursing homes are bankrupt in 13 weeks, and more than 70 percent exhaust their resources after a year. Medicaid covers extended care at the skilled nursing, intermediate, and custodial levels, but to qualify for Medicaid coverage it is necessary to "spend down" savings and investments, including investments in a family home, impoverishing the non-institutionalized spouse or dependent and pushing more people into public dependency.

Several demographic trends are likely to increase the need for long-term care. Life expectancy has dramatically increased, so the proportion of the population over 65, and particularly those over 75 who are most at risk for long-term care expenses, is growing rapidly. As people are less likely to be stricken by fatal acute diseases, they are more likely to fall victim late in life to debilitating or disabling conditions. Moreover, an increasing number of the old will be unable to depend on family to provide long-term care services. More women working, later marriages, fewer children, more divorces, and greater geographic mobility--these are familiar trends which, given the current predominance of family support in the provision of long-term care today, mean an inevitable change in the provision of this care in the future. Over the next 50 years, the National Center for Health Statistics projects that the nursing home population will increase more than threefold, from 1.5 million to 5.2 million residents.

Finally, the use of Medicaid as the principal third party payer for long-term care has absorbed a large proportion of Medicaid funds and put considerable strain on the funds available to support the non-Medicare poverty population. Currently, about three-fourths of all Medicaid expenditures are used to pay long-term care costs and other expenses generated by Medicare enrollees, leaving about one fourth for the growing number of non-elderly, non-disabled poor. The large and growing number of uninsured results, in part, from an increase in the number of people below the federal poverty level; but it also stems from a simultaneous decrease, due to eligibility restrictions, in the number of people covered by Medicaid. By 1983, Medicaid covered fewer than 40 percent of the poor, compared with 65 percent in 1976.

There are problems with access to two distinct types of long-term care services: access to adequate extended care services associated with episodes of acute illness; and what is more conventionally thought of as long-term care--the maintenance of individuals with stable but chronic conditions. Using the current array of services available under Medicare and Medicaid, there are ways to enhance access to extended care services under Medicare and prevent the pauperization of the elderly seeking nursing home coverage under Medicaid. But for long-term solutions to the problems of the chronically ill and disabled, it will be necessary to undertake a major restructuring of Medicare and Medicaid, including the creation of a separate public program for long-term care to supplement private financing mechanisms.

SHORT TERM IMPROVEMENTS

Short of a total reorientation of the Medicare and Medicaid programs, there are several ways that existing programs could be modified to reduce some of the inadequacies of our current system for providing extended- and long-term care services. The Medicare benefit should be restructured and administration improved to make extended care services more available for the elderly. In addition, for those who must use their own resources to cover large long-term care expenditures, we suggest an alternative to prevent the impoverishment of spouses and families under current "spend down" provisions.

Gaps in Medicare Coverage

Most Medicare enrollees purchase supplemental or "wrap-around" coverage, some with the mistaken expectation that it protects them against long-term care costs. However, because the benefits of "wrap-around" coverage are generally limited to services covered by Medicare, even with these policies most Medicare enrollees have almost no protection against long-term care costs.

There are several problems that restrict Medicare's usefulness for extended care services. First, Medicare has arbitrarily limited the definitions of covered skilled facility and home health services to restrict access to payment. Strict interpretations of what constitutes "skilled" care or, for rehabilitation patients, "rehabilitation potential," have led to the retroactive denial of many patient days in skilled facilities. Although Medicare offers 100 days in a skilled nursing facility, the average Medicare coverage of a skilled nursing stay is a mere 27 days. At the same time, narrow interpretations of the "intermittent" care requirement for home health coverage under Medicare has tended to disqualify those with more intensive skilled nursing needs. Thus, a patient may need too little "skilled" care to qualify for SNF placement, but too much to get access to home health benefits. It is important that the fiscal intermediaries be required to write their coverage criteria and make them available to providers and beneficiaries. This will promote understanding of the benefit and improve the assessments by all parties of the appropriateness of SNF and home health claim denials.

Making sense out of the coverage criteria for these services also should focus on sorting out where beneficiaries should be cared for when they have an acute episode and provide sufficient flexibility to use the appropriate level of services without arbitrary barriers. The original Medicare benefit was designed with the expectation that most acute care would occur in inpatient hospital settings. This is no longer true. To recognize the changes that have taken place in health care delivery, it will be necessary to relax the intermittent and home-bound requirements for home health, and eliminate, in whole or in part, the three-day prior hospitalization rule for SNF coverage.

For example, it has been suggested that the intermittent care restriction be redefined to allow for intensive skilled nursing or physical therapy, e.g., up to two visits a day for a limited number of days. In addition, Congress should reconsider the budgetary restrictions attached to the Secretary's authority in Sec. 1812(f) of the Social Security Act to waive the prior hospitilization rule for extended care. Finally, although the current focus on "skilled" care prohibits coverage of services for assistance with the "activities of daily living" (walking, eating) and the "instrumental activities of daily living" (shopping, preparing food), it has been demonstrated that appropriately managed community based services can prevent costly institutionalizations. In California, case-managed community based services have demonstrated costs about 70 percent of those in institutions. The AHA recommends providing community based waivers under Medicare like those now available under Medicaid, where, with the use of case management, it can be cost effective to provide community based services in place of institutional care. These changes could enhance the use of the Medicare benefit for post-acute extended care without exposing the program to unlimited liability, and without violating its essential nature as an acute care benefit.

As a consequence of what are perceived to be stringent, often arbitrary, and highly variable interpretations of the coverage rules, SNFs are often reluctant to accept Medicare patients, which impedes transfers from acute to less intensive settings and inhibits access to the SNF benefit. Furthermore, while the need for post-acute institutional care has been increasing, state governments, perhaps to limit their own liability under their Medicaid programs, have limited growth in the number of nursing home beds. Six states have imposed moratoria on the addition of new beds. Medicare needs to eliminate arbitrary barriers to the provision of needed skilled subacute services by hospitals. Where extended care services are needed but appropriate placement is unavailable, hospitals should be able to provide the services and be paid for them at the appropriate (i.e., skilled) rate.

The current structure of the copayment for SNF services has also become an obstacle to services under Medicare. Because the copayment is tied to the hospital inpatient deductible, which has risen dramatically over the past few years, over 90 percent of the daily cost must be paid by the beneficiary after the 20th day in a skilled nursing facility. This copayment needs to be separated from the inpatient hospital deductible so that it serves the desired purpose of controlling excess demand while still providing a fair contribution by the Medicare program to the cost of extended care.

Medicare provides extremely limited coverage of psychiatric services and insufficient coverage for the rehabilitation of stroke or accident victims. It is time to eliminate the 190-day limit for inpatient psychiatric hospital services as no longer necessary. With extensive utilization controls and cost-per-case limits on payment, there is no basis for perpetuating a two-class system of coverage for psychiatric and non-psychiatric illness. It is inappropriate to substitute a limitation on benefits for effective utilization review.

Finally, we believe it is time for Congress to reexamine the two-year waiting period for disability coverage under Medicare. For the permanently disabled, the two-year wait can cause severe hardship and discontinuity of care. Recognizing the potential cost of totally eliminating the waiting period, we recommend that a study be conducted of incremental modifications that could be made.

Subsidized Loans as an Alternative to "Spend Down" Requirements

Some individuals admitted to nursing homes return to their homes after a limited stay; others remain in the nursing home until death. If those individuals who are able to return to the community have been impoverished by the spend-down provisions, they are likelier to become permanent residents of long-term care institutions, at considerable cost to the public. Furthermore, when nursing home patients with non-institutionalized dependents are compelled to sell homes and consume income-producing investments, public assistance costs and nursing home admissions can increase. Moreover, the standard of living for dependents may be reduced to an indecent level. When an individual without dependents is admitted to a long-term care facility with little expectation of returning to the community, it may not be inappropropriate for him to use his savings to support it. The challenge is to develop a way of enabling individuals to draw on their resources that will not prevent them from returning to the community or force their families into public dependency.

As an alternative to the "spend down" requirements for Medicaid eligibility, a system of federal and state loans, guaranteed by an individual's estate, would allow spouses or dependents of individuals in long-term care facilities at any level (skilled nursing, intermediate, or custodial care) to qualify for public assistance by pledging their assets, or a percentage of their assets. The spouse or dependent would continue to enjoy the use of real property and the income generated by investments until he (or she) died or decided to liquidate the estate because he (or she) had entered a long-term care facility and had little expectation of returning to the community. Rather than spending down to meet an eligibility test, beneficiaries using this option could be required to meet annual cost-sharing requirements which could be tied to their annual income. This alternative is not without problems--e.g., in converting the real property posted as collateral into cash--but may be a viable and more humane alternative for Medicare beneficiaries.

LONG TERM GOALS OF PUBLIC POLICY

The financing of long-term care is likely to continue to be a shared responsibility of individuals, the private sector, and state and federal government. The AHA suggests three general propositions for a combined public and private strategy to provide for coverage of long-term care.

First, public policy should encourage individuals to provide for their own long-term care to the extent permitted by their income and, to the extent necessary, provide access to needed long-term care when individual resources are inadequate. Such a strategy would have to consider whether individuals should be required to spend their lifetime savings to pay for long-term care, or whether their estates should be protected. It may be necessary to distinguish between those individuals who were unable to make provision for long-term care needs, those who could have but chose not to, and those who sheltered their assets by giving them away to their heirs.

Second, the current institutional and medical bias for financing long-term care should be reconsidered. The non-institutional alternatives, including social and personal services as well as skilled care, can potentially provide superior care at lower cost. But, perhaps more important, the kind of long-term care provided will depend on the array of services available in the community. Some flexibility is needed in the financing of long-term care that will ensure access to needed services and encourage innovation in service delivery.

Finally, it is essential to consider case managment or some other systematic coordination of services, to combat the fragmentation that currently characterizes the provision of long-term care and to assure the continuity of care among service providers.

Private Long-Term Care Insurance

Several proposals have called for federal incentives to encourage private sector financing of long-term care to relieve the pressure on public programs. The development of private sector alternatives for financing long-term care can be encouraged through tax incentives as well as public and private demonstration projects. These initiatives should include efforts to increase understanding among the elderly and non-elderly of the inadequacies of current coverage of long-term care and the risk of needing long-term care.

Individual Medical Accounts (IMAs) have been suggested for self-insurance of long-term care. Although IMAs might provide a vehicle for financing a part of the care needed by future Medicare beneficiaries, they cannot form the principal source of funding, because they are likely to be used predominantly by upper income groups and because they do not entail any sharing of risk, which is essential to ensure adequate coverage and affordability of contributions.

The difficulties of privately insuring long-term care should not be underestimated. The major barrier to private long-term care insurance is the extreme uncertainty surrounding whether services will be needed, and the high costs of services if they are needed. Pre-funding mechanisms, such as the IMA, also must contend with the uncertainties caused by fluctuations in the rate of inflation, in the cost of long-term care, changes in life expectancy, changes in the incidence and prevalence of chronic diseases, and changes in delivery patterns for long-term care services. These uncertainties require some form of risk pooling over relatively large populations, suggesting that some involvement of government in the financing of long-term care may be necessary. Although commercial insurance companies have begun to enter the long-term care market, such insurance is still viewed as experimental. Their coverage tends to be narrow, focusing typically on nursing home care, and shallow, tending to cover only shorter stays (such as 3 months). As with all private insurance options, the coverage offered will tend to be limited to control risk, so many of the neediest will find such coverage unavailable.

There is a significant marketing problem for private long-term care insurance in that people generally do not understand the limits or nature of Medicare coverage. Most beneficiaries believe that their long-term care needs will be covered by Medicare. It is essential that the Medicare benefit and coverage be simple and clearly stated so that beneficiaries can understand the gaps in their coverage. Greater simplicity in the determinations of beneficiary copayments would also improve the ability of beneficiaries to assess their need for and the adequacy of private supplemental coverage.

Public Financing of Long-Term Care

Private long-term insurance and other private sector financing methods will reduce the need for public financing, but will not eliminate the need for public programs. Public and private initiatives address the needs of different populations.

Last year, the AHA's Special Committee on Care for the Medically Indigent, in examining the problem of medical indigence, found that the Medicaid program has drifted away from its original focus on acute care for the non-elderly poor, and has become instead a supplemental program of Medicare Part B buy-in and nursing home insurance for the elderly. In order to more clearly address the three separate needs that Medicaid has come to support, the AHA recommends dividing the program into three parts:

- Acute medical care coverage for the uninsured who are not eligible for benefits under Medicare--what we now perceive as Medicaid;
- A program to purchase supplemental Medicare Part B coverage for the low-income Medicare-eligible population. This program, which would round out the acute care insurance coverage of the Medicare beneficiary, would be funded out of general revenues of the federal government, and would simply involve the transfer of funds to the supplemental insurance trust fund;
- A program of long-term care insurance, funded by either the states or a combination of state and federal appropriations. This program would replace part of the current Medicaid program, would be designed to be compatible with emerging approaches to the private funding of long-term care, and would address the problems of the low-income Medicare patient unable to obtain private insurance or pay for long-term care out of savings.

In recommending this restructuring, the AHA recognizes the importance of the issue of long-term care, but acknowledges the limitations of current methods of delivery and financing. The AHA believes that better approaches need to be developed, and that by setting up a program devoted exclusively to long-term care, the search for innovative approaches such as case management or capitation may be encouraged.

CONCLUSION

It is clear that long-term care is destined to be a significant health care policy issue. Current public programs do not adequately meet long-term care needs, and with Medicare's limitations on extended care coverage, and Medicaid's emphasis on nursing home care, do not assure access to community services and do not encourage innovation in service delivery. In the short term, much can be done to enhance access to extended care through Medicare, and steps can be taken to prevent the impoverishment of the spouses and dependents of individuals who must now spend all their resources to become eligible for Medicaid coverage of nursing home care.

In the long term, public policy should encourage the private financing of long-term care services, in a flexible way that encourages the use of community resources. Although still experimental, private long-term care insurance shows promise. Nevertheless, there will continue to be a need for a residual public program of long-term care insurance for those with limited resources. A separate program to fund long-term care would relieve the current strain on provision of acute coverage to the poor under Medicaid, and could be structured to encourage innovative, community based services for the chronically ill and disabled.

apta American Physical Therapy Association

March 11, 1987

The Honorable George Mitchell
Chairman, Subcommittee on Health
Senate Finance Committee
U.S. Senate
Washington, DC 20510

Dear Mr. Chairman:

The American Physical Therapy Association (APTA) welcomes the opportunity to participate in the discussion of catastrophic coverage under the Medicare program and requests that these remarks be made a part of the record of the hearing held on February 28, 1987.

The APTA represents over 44,000 licensed physical therapists, physical therapist assistants, and students of physical therapy across the country. As health care professionals, our members are integrally involved in the delivery of services throughout the spectrum of settings in which health care is delivered. Consequently, we are very interested in the current initiatives which have been proposed by the Administration and others to address the problem of catastrophic health care coverage.

We applaud both the Administration and the Congress for turning their attention to this timely issue and we are pleased to be able to contribute to the search for solutions. How we as a nation deal with the catastrophic costs of illness today will go far to determine the viability of the Medicare program as an effective health care system in the coming years. This is especially important since Medicare assumes an added significance with each passing year as we become more and more involved with the needs of a rapidly expanding elderly population.

As we embark on the essential reevaluation of the Medicare delivery system, it seems that our major task is to determine where exactly the phenomenon of catastrophic costs is a pervasive problem. Then it would seem that we need both to identify solutions to the problem and determine the first steps to be taken in actually addressing it. These initial steps ideally will be the foundation on which we can eventually expand our treatment of the overall problem.

The primary question then becomes in which areas are health care consumers primarily faced with the problem of catastrophic costs? To some extent these costs arise in the context of inpatient hospital care. The largest out-of-pocket expense faced by most Medicare-eligible hospital inpatients is the deductible which Congress has currently stabilized at $520. While this deductible applies per hospitalization, it is not applied to readmissions that occur within sixty days of an earlier admission. This application of the hospital deductible significantly lessens its potential burden.

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The other instances in which hospital inpatients face significant out-of-pocket expenses occur when hospitalization exceeds 60 days and Medicare beneficiaries become obliged to contribute coinsurance amounts. In these instances, out-of-pocket expenses can become truly significant and warrant description as catastrophic costs. Yet, it is a relatively small percentage of Medicare beneficiaries who find themselves in this unfortunate situation (158,000 or .5% in 1984) and the hospitals have a powerful incentive under the prospective payment system (PPS) to discharge patients long before this can occur.

Despite the fact that the percentage of Medicare beneficiaries who would benefit from this change is small compared to the larger group of Medicare beneficiaries as a whole, the costs to these beneficiaries can be truly catastrophic and a remedy is definitely in order.

A larger question though is raised by inflated expectations. Much has been made of the attempt to devise an approach to catastrophic coverage and this, coupled with a lack of understanding about what the Medicare program does and does not cover, recommends that some further steps toward dealing with catastrophic costs be taken.

Nor need we look far afield to identify areas in which steps could be taken. At a time when hospitals have every incentive to discharge patients as soon as possible, the need for alternative care is increasing by leaps and bounds. The result is an overloaded alternative care system which is struggling to keep its head above the water. Symptomatic of this phenomenon is the fact that nursing home stays account for over 80% of the expenses incurred by those elderly persons who experience over $2000 per year in out-of-pocket costs for health care; yet, Medicare and private insurance combined paid less than 3% of nursing home costs in 1985. Symptomatic also of this phenomenon is the fact that home health care denials have rapidly increased since the implementation of the PPS, rising from 1.2% in fiscal year 1984 to 6% in fiscal year 1986.

Clearly, the larger problem of catastrophic costs is not found within the hospital. Rather, it is found once the patient has been discharged and finds herself unable to receive as a Medicare benefit the care that she needs. This is the heart of the problem of the catastrophic cost of health care, and it is here that we urge that additional steps be taken to provide real relief.

To maintain a logical progression of improvement, we suggest that skilled nursing facility benefits under Medicare be addressed and made more responsive to the needs of patients discharged from the hospital. Currently, coinsurance for skilled nursing facility care is required for days 21 through 100, and the amount of coinsurance is based loosely on the average national cost of a hospital day. The result is a coinsurance amount of $65 per day for each of days 21 through 100, an amount which in some instances is practically the same as the amount required from uninsured patients.

This formula reduces the availability of the skilled nursing facility practically to a benefit in name only. We suggest that the coinsurance calculation be based on a percentage of the average cost of a day's stay in a Medicare skilled nursing facility, that the coinsurance be paid up front so that all beneficiaries who use the benefit share in the financing of the change. We further suggest that the benefit period be extended from 100 days to 150 days, so that those beneficiaries in need of this transitional care from the acute hospital phase of their illness or disability to the noninstitutional setting of home care can truly benefit from it and not be bankrupted in the process.

Unless the initial steps taken to address the catastrophic costs of health care include more than simply dealing with the costs of acute inpatient care, we risk a general but very real disillusionment on the part of the Medicare beneficiaries whose hopes have been raised by this debate and the publicity surrounding it. While it is true that catastrophic costs can and sometimes do arise in the context of acute inpatient care, those instances are limited in number and the relief that is contemplated will go unnoticed by the vast majority of Medicare beneficiaries. To carry reform one step further and address some of the concerns which are involved in the setting of skilled nursing facilities, the first truly significant area where catastrophic costs appear, will send a message of good faith to those in need of that reassurance.

Beyond this, we recognize that, while the Medicare program is in need of other and more sweeping reforms, not everything can be done at once. A system which has evolved over a period of 20 years is not going to be revolutionized overnight. Yet, there are numerous other areas in which the Medicare program needs to be altered if its beneficiaries are to be protected from the catastrophic costs of health care over both the short and long term.

The area which comes to mind immediately after the hospital and skilled nursing facility is home health. This benefit is likely the most severely beset health care setting in the Medicare system today, and we have already noted the tremendous increase in denials for home health agencies.

There is little question that this can be ascribed to a combination of the effects of the earlier discharges resulting from the PPS and the lack of meaningful coverage under the current skilled nursing facility benefit. Yet, even if the skilled nursing facility benefit is strengthened, there are a number of inherent barriers which unjustifiably restrict the availability of home health care.

We urge that Congress take the steps necessary to reverse the current deluge of home health care denials and that it address use of restrictive interpretations of key terms such as "homebound" and "intermittent." The intermediaries are being pressured to use these and any other means available to serve as the basis for denials of this care.

A natural result of the deemphasis of institutional care is an increase in the demand for home care. Consequently, we feel that home care should be encouraged rather than denied. Steps should be taken which enable the ill and disabled to be adequately cared for in their homes rather than forced to once again enter the other end of the spectrum as recipients of acute care.

Along these lines, we encourage adequate coverage of self-help and safety equipment which will enable Medicare beneficiaries to remain in their homes. While there is a durable medical equipment benefit under Medicare, it does not extend to equipment of this nature. The Health Care Financing Administration has repeatedly taken the position that self-help and safety equipment do not meet the statutory definition required by the durable medical equipment benefit in that these items are not primarily and customarily used to serve a medical purpose and that, therefore, there is no statutory authority for coverage. The expansion of the durable medical equipment benefit to include self-help and safety equipment would serve to remove a very real barrier to effective long term care in the home setting.

As Congress turns its attention to the issue of long term care, we suggest that a prime area for reform is the current Medicare emphasis on rehabilitation potential. The lack of this potential often results in the determination that the care being provided to Medicare beneficiaries is custodial or maintenance care and, therefore, not covered under the Medicare program. While this approach may indeed save Medicare dollars in the short term, it encourages the deterioration of the patient to the point where acute care episodes are repeated. It would seem in the better interest of all concerned to maintain the patient's level of functioning and thus prevent the need for more expensive covered care at some inevitable point further along.

Finally, we question the viability of any reforms which heavily rely for their effectiveness on the largely unrefined concept of "covered services." This is especially the case under Medicare Part B. It has been our experience that in all too many cases, "covered services" are essentially what the intermediaries and carriers determine them to be. The definition of "covered services" often hinges upon the concept of "reasonable and necessary" which in turn is fertile ground for subjective interpretations upon which to base denials of coverage. While there is no argument that services rendered should be medically reasonable and necessary for the treatment of the patient, those determinations should not rest on considerations such as how many dollars the intermediary needs to save in order to maintain a favorable contractor performance evaluation status. The determination of what is reasonable and necessary should be based on professional health care criteria and not be the outcome of an economic analysis.

Frequently the opinion of one intermediary, reviewing the coverage primarily from a financial perspective, bears little relationship to that same determination made by another intermediary. Nor do decisions made by claims reviewers within the same intermediary necessarily follow discernible patterns. This subjectivity, biased as it often is by financial considerations, gives rise to a patchwork of coverage which, even though it may be evened out through the appeals process, causes great uncertainty as to what is covered and introduces considerable time and expense to the entire process by increasing the number of appeals. This is a serious impediment to the provision of care under the current Medicare system and we urge that whatever new approaches are superimposed on that system not incorporate the flaws which are presently identifiable.

In summary, we urge that the steps focusing on catastrophic costs, extend beyond the acute care hospital setting so that relief can be provided where it will be most meaningful. This would involve at least some initial improvement of the skilled nursing benefit. Beyond this, we urge the Congress to look to improvements in the area of home health care, and we suggest that significant progress in addressing catastrophic costs can be achieved by eliminating artificial barriers in the current Medicare program.

Sincerely,

R. Charles Harker

R. Charles Harker, Esq.
Director of Government Affairs

RCH/fm

Statement of
American Veterans Committee
to the
Subcommittee on Health,
Senate Finance Committee on Health-Care Programs

February 24, 1987

The American Veterans Committee appreciates the opportunity to have its views brought to the attention of the Committee on the urgent question of "catastrophic health insurance."

AVC is a national organization of veterans of the United States armed forces, organized during World War II, which also includes veterans from World War I, Korea, and the Vietnam War.

The AVC is very much concerned about the current situation of health care in our country. The United States is the only industrialized nation in the world that has no system for guaranteeing health care for all. AVC has long been on record in favor of a national health insurance that would see to it that every American has the health care that he or she needs.

AVC's National Affairs Platform calls for:

"1. Increased Federal expenditures for research in the prevention and care of illness.

"2. Expansion of medical insurance and group medical care plans, including a plan for national health insurance.

"3. Expansion of public health facilities and services, hospitals and nursing homes, without regard to race, color, ancestry, national origin, religion or sex."

We have a population of aging Americans. The aging population is the fastest growing population in the nation. U.S. Census Bureau statistics for the year 2000 show 35 million people over 65 and 5 million over 65. By 2000 two out of every three males over the age of 65 will be veterans. Yet our health-care provisions have not taken account of this demographic reality. For veterans this has become a startling reality with the recently imposed limitations on the availability of the VA hospital system to veterans.

A 1985 Report based on the 1983 Survey of Aging Veterans indicated that two-thirds of veterans experience limitations in their activities due to disability or poor health, and it was urged that the VA should plan for those veterans over 75. These statistics reveal the extent of the problems of the aging veterans population. But that VA system which veterans have traditionally counted on will not be there for them--unless their illnesses are service-connected or they pass a means test.

This means that hundreds of thousands of older veterans who would not have had to seek health care services will now have to turn to other sources. Even if their incomes are above the poverty level, if they are not employed or do not have good private health care insurance plans, they find themselves out in "no-man's land." They, like their counterpart non-veterans, will find themselves vulnerable to the "catastrophic" impacts of serious and long-term illnesses which beset the elderly and which drain their meager resources and wipe them out financially.

Furthermore, there is strong evidence that the safety net provided by the Medicaid program is full of holes. It is available to less than 50 percent of the population living below the poverty level. Numerous studies have indicated that the amount of health care received by the insured population and the uninsured population is striking. Those who need health care most often are the ones least likely to get it under current laws and regulations.

Therefore, the Administration's proposed cuts in Medicare and Medicaid are irresponsible and can only exacerbate an already horrendous situation. When the AMA, the American Nurses Association, the Federation of American Health Systems, and the American Association of Retired Persons, get together to protest these proposed cuts in the Medicare-Medicaid programs, it is time to pay attention.

When the Department of Health and Human Services held hearings around the country on Secretary Bowen's proposals for the elderly to be able to meet the costs of "catastrophic illness," AVC's National Affairs Chairman Ben Neufeld testified in Oakland. We are attaching his detailed testimony to this Statement.

Essentially, AVC supports modifications to the Medicare porgram to make it more sensitive to the needs of beneficiaries with high-cost health problems. AVC does not, however, support the concept of a Medical IRA, primarily on grounds of financial impact. Most important, we urge full attention and relief be given to the health care needs of persons with low incomes, and those with no health insurance, people for whom relatively low costs for health and hospital care are "catastrophic."

Two major criteria must be used in developing such a program. They are:

-- Fairness. It must be, and appear to be, of help to all members of soceity who need help in meeting health care expenses, in proportion to their need.

-- Universality. It must be available to all persons in such need, wherever in the country they live. Unlike the present Medicaid program, your solution cannot be dependent upon state largess, and we believe your Committee should recommend a wholly-Federal program. Some states have shown that they will provide only the most minimal program; states have also demonstrated that they will use their political power to prevent imposition of the Federal penalties prescribed by law as inducements to them to implement programs.

It must be emphasized that any serious proposal must include protection for older Americans for long-term care, such as nursing home care. Neither lower nor middle income families can finance nursing home care, with annual costs averaging $22,000 a year. Any plan for "catastrophic health insurance" must include provision for elderly veterans and non-veterans who must draw upon lifetime savings (if they have them) to finance the expensive long-term care often needed in the so-called "golden" years. Both acute care and long-term care costs are truly "catastrophic" for the older generation. It is incumbent for the nation to address these unmet problems.

We owe Secretary Bowen a debt for opening up this issue at a time when the health and well-being of millions of Americans is being jeopardized by the lack of adequate private and public health insurance. While Dr. Bowen's proposals are welcome, they do not go far enough to meet the problem. We urge the Congress to enact the needed legislation so that elderly Americans with lower and middle income resources may receive the amount and kinds of health care that they need.

Statement of the

American Veterans Committee (AVC)

1735 DeSales street NW Washington, DC 20036 202 639 8886

Before the

Private/Public Sector Advisory Committee on Catastrophic Illness
Department of Health and Human Services

31 July 1986

Presented by

Ben Neufeld Member, National Board
Chairman, National Affairs Commission

2000 Linda Flora drive Los Angeles, California 90077 213 471 4032

I am Ben Neufeld, a member of the National Board of the American Veterans Committee (AVC). Avc is a national organization of veterans of the United States Armed Forces, organized during World War II and including also veterans who served during World War I, Korea and Vietnam. Our first national convention was held just forty years ago.

We appreciate the opportunity to participate in this forum. Our statement will touch upon the two matters mentioned in the general description of Secretary Bowen's proposals circulated by the Department and then discuss the nature of "catastrophic illness".

First, however, we would point out that this series of forums would not have been necessary - certainly not in its present form - if the United States had some form of national health program, a mechanism through which all Americans would be assured access to health care and the means of paying for it without regard to the circumstances of any individual patient.

Of the Secretary's proposals, the first concerned the Medicare program and modifications to make it more responsive to catastrophic illness defined in terms of the length of a period of illness, therapy and rehabilitation. This is a good idea. We have never been happy with the need for private, outside insurance to cover a significant portion of what Medicare was advertised as providing for the elderly person. As an alternative use of money now spent on Medigap insurance premiums, the idea of buying "deductibles insurance" or insurance for non-covered services makes sense. Of course, it may be a while before such insurance is available at reasonable cost for appropriate bundles of services. Long-term care and dental care are available only for selected groups now; the costs are high and the dental benefits are largely packaged for young families. So, more work will need to be done before specific alternate premium ideas can be evaluated with any precision.

Another alternative which has been under discussion for some time should also be explored: broadening the services which are included in the Medicare package, particularly dental services, prescription drugs and intermediate-level long-term care. Each of these can cause a major drain of the resources of an elderly person and his or her family. We call upon the Department to publish such actuarial information as it has and can develop on these three services so that we and all interested parties can analyze it and offer recommendations for Federal and other action.

An aspect of the Secretary's proposal for Medicare modification particularly worthy of mention in this age of reducing hospital stays is the reduction of coinsurance for skilled nursing care. One reason we consider this important is that it should reduce confusion about what Medicare will do for a beneficiary. Another is that it should make more apparent than it is now what Medicare does not do with respect to long-term care. Most important, of course, is that, while skilled nursing care is a need for many older patients, it is a resource in short supply in many communities; this recognition of the need may help expand the availability of such care. The economics of long-term care are such that relatively small differences in reimbursement seem to have relatively large consequences.

The other of the Secretary's proposals is the Individual Medical Account (IMA). Our National Board discussed the concept some years ago and rejected it, and we still find in the idea not enough positive aspects to warrant the tax loss to the Treasury and our support. Let us set forth our objections.

First, the IMA would, like the familiar IRA, have a maximum contribution every year. Whether this is expressed as a flat dollar amount or as an amount related to a person's maximum deduction deduction from wages or salary under FICA, those with the least available income would least be able to take advantage of the shelter and least be able to finance their health care needs. That is, the IMA would benefit the middle class without providing commensurate benefit to persons of lesser income, those who most need the assistance. Thus, it is not, as is suggested, an across-the-board partial solution to the potential financial impact of health costs.

Second, the IMA as described by Dr Bowen would be used to pay for long-term care. The present cost of such care is estimated to average $25,000 per year, including both skilled and lower-level care in a facility. Home care generally represents a lower total cost and a lower cost per patient, but this is true largely because it is intermittent. Unit costs, however, are not greatly lower than equivalent care in nursing homes for many services. With the cost to the patient as the standard, then, the amount of money available to pay for long-term care would not buy very much care unless the central depository could count upon continued high interest earnings. In this sense, it could fall upon hard times just as the Hospital Insurance Trust Fund has, to the detriment of its beneficiaries.

If the IMA deposits, including both worker deposits and interest earnings, are to be available also to pay for other kinds of health care, then predictability is even further compromised.

Third, Secretary Bowen's description of an IMA is fairly straightforward. However, Peter Ferrara of the Cato Institute has devised a far more complex administrative scheme relating deposits, earnings and expenditures to Medicare utilization, deductibles and coinsurance and to cash withdrawals. This scheme reverses the simplification in the Medicare modifications proposed by the Secretary and make it difficult for an individual to plan utilization of the IMA and Medicare benefits. There is also some possibility that the IMA will be able to work only on an annual cycle, at least as far as deposits are concerned. Because illness and disability do not respect calendars, this could further disrupt understanding and utilization. We do not see simplification as a goal in itself, such that benefits should be dropped to enhance understanding, but, other factors being equal, the simpler program is the more desirable.

Finally, we want to discuss what "catastrophic illness" is. The term currently refers not to the nature of an illness but to the cost of care for an illness. Some illnesses with catastrophic effects do not involve catastrophic costs of care. At one time, the subject was known as "the catastrophic cost of illness."

Then it became convenient to define the term [illegible], however, the insurance people and academic researchers tended to use thresholds as standards and to establish levels of cost that would be catastrophic. In fact, [illegible] depending on personal and family insurance coverage, employment-related health benefits, assets and willingness to reduce their own standards of living. The result is that catastrophic or "major medical" coverage becomes effective only after a deductible of ten or twenty five or more thousands of dollars, the higher the deductible keeping the lower the premium. Notice, however, that we are talking about multi-thousands of dollars as the threshold.

But, consider that not all people who are likely to receive care of catastrophic cost are regularly employed in places where health insurance is offered. Many low-income people work where only the most basic health insurance benefits are available, at considerable cost. Right now, there is a significant population which lost its coverage when it lost its employment. And, the long-term unemployed and even many employees of marginal business and industrial firms and household employees have no access at all to insurance at affordable prices. For them, the threshold is much lower.

For some of these people, Medicaid may be available. With cutbacks in federal and state funding, however, the Medicaid-eligible population has been shrinking, at different levels in different states.

Also, for some of these people, a health care expenditure of one thousand dollars may be termed "catastrophic". The practical threshold may be only a few hundred dollars – if the provider will accept small payments over time.

Furthermore, Medicaid reimbursements in some states are so small and slow and the paperwork said to be so burdensome that patients who have Medicaid coverage are not welcome in the offices of many physicians, making Medicaid coverage a less important factor in [illegible] than ability to pay. This is a matter to which this Committee should devote more attention.

To maintain perspective, we remind the Committee that it was only with the creation of the Medicaid program that the term "medically indigent" came into use.

It describes those people who, although they have low incomes, are able to meet all of their needs until they incur major health care costs. These "medically indigent" people could be helped with their health care obligations even though they were not recipients of financial grants under one of the Federal-participation assistance programs. In other words, in 1965 there was recognition that catastrophic cost of health care involved costs lower than thousands of dollars for some people. Still, state coverage of the medically indigent was made voluntary while coverage of those receiving aid under the public assistance categories was made mandatory. Only a few states covered the medically indigent at first, but the number increased gradually until the last few years, when budget crises started to cause states to restrict Medicaid in various ways, including dropping the medically indigent population altogether.

But, the problem remains. We therefore suggest that your Committee specifically define its mandate to include the development of guidelines that will permit the Secretary to create and evaluate proposals for having the catastrophic cost of illness covered by programs that will truly serve families of modest and low income and those who lack access to affordable insurance.

It is vital that you do this quickly, for two reasons. One is that you do not want to run out of time yourselves and you will probably want to collect and study more hard data and opinions before you submit your final report to Dr Bowen.

The other is that, even as you are conducting your own study, others in the Department are preparing legislative and regulatory proposals that would further restrict the availability of Medicaid assistance. We refer you to the New York Times of 13 July. The story does not say whether the Health Care Financing Administration (HCFA) or some part of the Office of the Secretary is leading this effort, but it suggests that some old issues, once resolved, are being reopened in order to reduce the budgetary impact of Medicaid, even at the cost of impoverishment of some portions of our society. This is something which AVC, and, we think, Americans generally emphatically reject.

AVC, having urged you to undertake more work which will be perceived as unwelcome by some with whom you have to cooperate, offers to try to be of assistance if you call upon us for our help.

CHWAT/WEIGEND ASSOCIATES
CONGRESSIONAL & GOVERNMENT RELATIONS
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WASHINGTON, D.C. 20001
202/638-6400

February 27, 1987

Senator George J. Mitchell, Chairman
Senate Finance Committee's
Health Subcommittee
U.S. Senate
Room SD-205
Washington, D.C. 20510

Dear Chairman Mitchell:

On behalf of our client, the National Association of Companion Sitter Agencies and Referral Services (NACSARS), we are submitting the following comments for inclusion in the permanent hearing record for the February 24, 1987 long-term health care subcommittee hearing.

We understand that the Subcommittee's topics for review at this hearing included types of long-term care services and current programs for providing and financing long-term care. NACSARS forms an important part of the home health care industry, and we would welcome the opportunity to have a witness appear before the Subcommittee. After a review of the witnesses testifying at the February 24th hearing, we request a second day of hearings at which time you should focus on other forms of long-term care services being provided around the nation to the elderly. At that time, we would provide an insight into the type of NACSARS members who have worked in this area for decades. In lieu of this, we are submitting written comments and hope that NACSARS can have an active part in determining issues and programs that affect their members and the home care clients they serve.

NACSARS represents hundreds of privately-owned, for profit referral services and agencies that specialize in companion and home care services for the elderly, long-termed infirmed and children. The members of the Association range in size from small businesses to firms with annual gross sales from service fees of over one-million dollars, the latter of which schedule referrals for home care services of between 400 to 500 independent contractors each day.

Organized in February, 1978, NACSARS membership is limited to owners, operators, or directors of a company or agency which refers individuals to another person, firm, partnership, or corporation who can use that individual's services for a fee. The Association meets annually, publishes newsletters, conducts seminars, workshops, and schedules events beneficial to the membership. Some agencies have been operating for between 20 and

0 years. Traditionally, agencies were known as nursing registries. Most are licensed as employment agencies.

The members of NACSARS are not Medicare-certified home health agencies, because Medicare regulations do not provide for direct reimbursement. However, independent contractors who are referred by NACSARS-member referral services provide their clients with quality, professional services at a much reduced cost, compared to other home health agencies. For example, in Connecticut the Medicare-certified agencies ranged in price for home health aides from $9.25 to $11.50 per hour, with a four hour minimum, while the independent contractors referred by NACSARS-type referral services have prices around $6.20 per hour with no minimums. These cost comparisons are similar throughout the country, and could have a significant impact on home health costs for the future.

NACSARS believes that the general public should be free to choose independent-contractor type home care providers, particularly if the care needed is minimal. Nurses registries and companion sitter agencies throughout the country are in the business to refer such independent contractors to chronically ill, but essentially stable, individuals. Such independents, referred by registries and companion sitter agencies, can offer services at very reasonable prices. Why should senior citizens or families who care for the elderly at home pay higher prices for services provided by high-overhead agencies with many layers of "supervision" when none is required, much less wanted? This "supervision", NACSARS believes, should best be handled by a patient's doctor and a competent family member. In this regard, NACSARS also has a code of ethics and standards of operations which are attached at the end of this testimony.

The more expensive agencies have the advantage of direct reimbursement of their fees by insurance or, in some cases, by Medicare. This type of reimbursement is not available at present for private referral services and the independent contractors who are referred by such referral services. A gap in society is developing called a "no-care zone" where middle class Americans cannot afford the minimum services they need to remain at home. They are forced into higher-priced custodial services through expensive agencies, because that is the only type of agencies which are reimbursed by insurance or Medicare. The rate payers and taxpayers all pay in the long-run.

NACSARS continue our efforts to provide quality service and urge that Congress protect and support us.

Recommendations:

1. That nurses registries or agencies currently providing these

services be protected. There are thousands of these agencies and thousands of families currently being served.

2. Since many of the people who work for Medicare-certified agencies also work through NACSARS agencies, it should be recognized that people referred through NACSARS-type agencies frequently have the same qualifications, easily-checked work records and previously-developed skills in dealing with the frail elderly. Efforts should be made to educate health care professionals regarding the services provided by companion sitters and licensed personnel referred through registries.

3. That maintenance of the "independent contractor" status, and the reduction of paper work and record keeping, are positive elements which permit agencies to provide low cost services, and to allow agencies to refer older workers. We support the efforts of the AARP to provide financial aid through insurance directly to the family; thereby allowing more families to contract directly with low cost, quality health care independent contractors.

4. That Congress continue to work towards the elimination of abuse of the elderly, and that guidelines be developed to strengthen the role of the independent agency in those areas, particularly as to training opportunities and funding.

5. That realistic studies continue to determine the savings accomplished by keeping the patient in the home environment, and pilot studies be conducted and monitored by the community, not by outside agencies such as the National Association for Home Care, who are on record as opposed to the use of independent contractors.

6. That the contribution of independent contractor workers be recognized and acknowledged, and that the family retain the right to supervise the care of their loved-ones and receive financial assistance directly through tax credits or any reasonable method of reimbursement approved by Congress. There is no reason to suppose that the average American is incapable of determining quality of care or following the instructions of their physician regarding long-term care needs.

7. That Congress be aware of efforts made to eliminate this independent contractor/referral service industry through

state regulations and licensing requirements, such efforts are undertaken with callous disregard of the effect on those who would face medical bills that would double overnight, and would have no practical effect on quality care.

8. That older Americans could and should be permitted to continue work and suppliment their Social Security payments. It has been our experience that this work is usually suited to the displaced homemaker whose natural homemaking and nurturing skills can be utilized, affording her personal satisfaction. More and more workers are able to return to the marketplace, conribute to the tax structure, get some personal respite from the care of their parents and earn the necessary income needed to keep "mother at home".

NACSARS members would like the opportunity to provide additional information on these matters to you, your staff and other members of Congress during the coming months.

Please feel free to call on us if you have questions regarding the items outlined in this letter. We look forward to working with you in this most important matter.

Sincerely,

John S. Chwat

JSC:jms
Enclosure

National Association
of
Companion Sitter Agencies and Referral Services

801 PRINCETON AVENUE, S.W. — BIRMINGHAM, ALABAMA 35211

CODE OF ETHICS

1. We will strive to maintain the integrity and quality control of our industry/profession.

2. We will support and protect the individual rights of our clients.

3. We will promote those activities which are primarily consumer oriented.

4. We will advocate quality health care services with a secondary emphasis on cost effectiveness.

5. We shall pursue those research and educational activities that will increase the knowledge of all NACSARS affiliates on a national level relating to changes and advances affecting our profession.

6. We will strive to educate and work in conjuction with those in politics in order to assist them in making effective decisions governing our industry.

National Association
of
Companion Sitter Agencies and Referral Services

801 PRINCETON AVENUE, S.W. — BIRMINGHAM, ALABAMA 35211

STANDARDS OF OPERATION

1. Members will obtain and maintain licensure and/or certification according to state and federal guidelines established. Also, proper DDD bonding should be secured.

2. Referrals will be sent out in compliance with physician directives. In cases where such directives are not available, referrals will be governed by criteria in each State's Nurse Practice Act. When Nurses Aides are requested in a home, an RN evaluation of patient status will be completed within 48 hours of initiation of care to determine whether or not the services being requested are appropriate.

3. a) Placement of referrals will be determined and/or supervised by a Registered Nurse.

   b) Companion/Sitter referrals will not be permitted to perform duties within the scope of nursing and therefore, a Registered Nurse supervising the referrals will not be necessary. However, these such agencies are encouraged to seek consultation arrangements with a licensed Registered Nurse.

4. Nurses Aides referred shall be required to have an accredited Nurses Aide course in areas where available. Also, when state certification is obtainable, this shall be the criteria. In areas where neither of the above is available, one year experience under supervision in either a hospital or nursing home shall be the criteria for placement.
   In addition, it is preferable even with those individuals who have obtained state certification, to have a minimum of at least one year experience either in a hospital or nursing home under supervision.

Cont.:

STANDARDS OF OPERATION

5. All nurses and/or nursing assistants referred shall be currently licensed according to state regulation; also, CPR certificates shall be required in the areas where available. The agency shall be responsible for maintaining proper records of such licenses and certification.

6. References both work and character related should be actively pursued an acquired before any applicant shall be referred for services.

7. A working history shall be kept and maintained including client names, location and medical problems along with any positive or negative feedback relating to the individuals performance.

218 Devron Circle
East Peoria, IL. 61611
March 1, 1987

DATE: February 24, 1987--beginning of hearing

TO: William J. Wilkins, Staff Director & Chief Counsel

FROM: Carol Miller, Housewife

SUBJECT: Long-term Care

Our country certainly needs a good plan for long-term care. I certainly hope some of the plans already introduced will receive some merit--especially those for nursing home care.

It is a known fact that most elderly patients entering nursing homes receive minimal or no coverage for serious medical conditions because of the reductions in Medicare. It is also a known fact that there is an increase in non-covered medicare payment denials, and I found this out because I asked nursing home personnel. The shock that people over 65 have when they find out that medicare does not cover nursing home bills is devastating. Then another shock hits when they find out that they must exhaust their savings to qualify for medicaid. However, there are those that do not have to worry because they have excellent medical Ins. that may continue for them after their last day of work or they have private Ins. for long-term nursing home care that they can afford.

Let me give you an example of what a typical conversation is like in my neighborhood. This is a recent comment from a neighbor: "We are moving into a retirement center soon and the center has a fine nursing home as part of the complex, and if we should need nursing home care and medicare won't pay, we have our excellent Caterpillar Ins. that will pay." Then another neighbor pauses and says, "Well, we don't have any great yellow Father in the sky (meaning Caterpillar Tractor Company) to fall back on, so we'll have to go on welfare if we have to go to a nursing home." This area where I live has a big company called Caterpillar Tractor, and it is a known fact that they pay very well on all medical bills submitted for hospital and nursing home care. There are many in our area that are jealous of those workers that have such exceptional medical security. Also, in this area, those without Caterpillar Medical Ins. have to pay the higher medical bills that are increased often when Caterpillar employees receive an increase in earnings. The point I am trying to make is that it is very unfair for some nursing home residents to have to suffer financially while the Caterpillar nursing home residents have good financial help because they worked for a strong and powerful company. Many of these people that have difficulty paying nursing home fees have worked for good companies too, but since they were not as big or powerful as "Cat" or their work medical Ins. ended with their last day of work, they don't have the resources. This makes me upset. This should not be in a country as great as ours.

Another problem with long-term care is that those that are able to pay for their care out of their own pockets really have to watch their budgets, and some of these people would love to be able to pay for additional services available in the home that are not included in the monthly nursing home base fee. These services could be Physical Therapy, Speech Therapy or Occupational Therapy (sure to be denied by Medicare part B), and no doubt would help many loved ones in a nursing home. We all know that in many nursing home situations there is one loved one at home paying the bills for another loved one in a nursing home and he/she can really see a needed nursing home service for the condition of the patient, but can't afford the extra charge. Now the patient on public aid gets that additional service because he/she needs it. This does not make sense to me. If I am wrong, please inform me.

The reason I am writing about the need for nursing home care in addition to the acute care hospital plans, is because when speaking about the elderly, a bigger percentage of expenses do not go to the hospitals, but to nursing homes. I don't believe an Alzheimer's patient can stay in a hospital very long and when they need a nursing home they also need financial help and where can the family go? If the patient remains home, the caring person certainly needs some help. Is there any? Those that oppose such care should take an Alzheimer's patient home for a week or perhaps visit with Roswell Gilbert. He is the man in the state penitentiary in Avon Park, Florida who ended his wife's long suffering from Alzhiemer's disease and osteoporosis. I have not cared for an Alzheimer's patient, but I have for an M.S. patient (not a relative), and it certainly was an experience that I will not forget. I got very exhausted and at times I had to pray for more patience. I pray that some help will be available in the future for patients with difficult progressive diseases. The caregiver desperately needs help too. Perhaps Roswell Gilbert was crying for help as a caregiver at home every day and none was within reach--not anywhere. Please give this serious thought.

Many Americans have known for a long time that their savings are threatened when a catastrophic illness occurs. They know that within a year in most long-term care facilities they have nothing left except perhaps a monthly social security check or pension check. This means they can't pay the facilities fee and must go on public assistance; and if they have a spouse, the spouse may also have to seek public assistance. These people have pride, and hate to be on public assistance, but what resources are left for them?

I am aware that many people do buy Medicare Supplement plans. They pay high premiums for these plans, and most of these have good ratings according to the Ins. industry, but the problem lies again with medicare. Since medicare does not approve the cost of many medical procedures neither will the supplement pay. Thus, some patients are still left with high out-of-pocket expense. It has been said that today, people on medicare, pay more out-of-pocket than before we had medicare. I'm sure it's true. Then the inflation in medical costs is 8 percent, so we have to dig deeper in our pocket until all our money is gone. Perhaps the Ins. premium money that is affordable for some should be discontinued and vested for only medical use, since the money spent for many Ins. premiums today is of no help when needed.

I would like to see a plan that would expand medicare coverage for nursing home care and for custodial care of some kind. I would also like some plan to help the elderly with prescription drugs and good physical exams. We owe it to our Senior citizens. The way it is now, the drug companies rob their pocket books. We must accept the fact that the current level of need must focus on more immediate solutions. The solutions for future generations can continue to develop as we explore new solutions.

I believe one of the immediate problems is working out a financial arrangement for long-term care that is affordable for today's elderly, so that any spouse remaining has some money left for his/her own medical care. I also believe that all elderly in the U.S. should be given a prescription card for prescription drugs. Then they will not have to say, "Why should I go to a Doctor, I can't afford the drugs anyway." Yes, some Ins. companies have such cards, but not all elderly can afford the premiums for the extra, etc.

In conclusion let me say that we need to have better long-term care plans or we will be a country that only offers medical care to the very rich or the very poor. Let's erase the growing fears we have today because we don't know how to face the uncertainties of tomorrow. Let's give long-term care as much attention as we give to defense spending. If we do, then we will have some very good solutions.

cm

Carol Miller

NATIONAL
ASSOCIATION
of
COUNTIES

440 First St. NW, Washington, DC 20001
202/393-6226

March 2, 1987

The Honorable George Mitchell
Chair, Senate Committee on Finance
SD-205 Dirksen Senate Office Building
Washington, DC 20510

Dear Senator Mitchell:

The National Association of County Health Facility Administrators (NACHFA), an affiliate of the National Association of Counties, appreciates the opportunity you have extended to us to submit written testimony for inclusion in the record of your Subcommittee's Hearing on Long Term Care, to be held on Tuesday, February 24, 1987. It is our hope that circumstances will permit us to present oral testimony and respond to questions from Subcommittee members if you continue these hearings at a later date.

NACHFA is an association of men and women who administer county nursing homes. These are the nursing homes which serve the poorest and sickest portions of our aged population. They are publicly funded and accountable to elected county commissioners. While such homes have not been highly visible in the national discussions of the nursing home industry, they nonetheless form an important part of that service delivery system, numbering approximately 900 homes throughout the country.

In times past, county nursing homes were sometimes characterized as "poor farms" of substandard quality. Whether that was ever an accurate portrayal or not, the fact is that today's typical county nursing home is a modern facility with trained, qualified staff. There are, of course, some exceptions, as there are elsewhere in the nursing home field. But by and large, the men and women who work in county facilities are dedicated to the welfare of their residents and anxious to continue to improve the lives of those entrusted to their care. Unfortunately, in discharging that mission, certain institutional impediments have worked against the best interests of our residents.

For example, current federal law prohibits supplemental Security Income (SSI) eligibility for residents of public facilities. (20 CFR 416,231). This prohibition applies to facilities with more than 16 beds and was rightfully intended to remove financial incentives for inappropriate institutionalization of SSI recipients who could better be served in a community setting. We have no quarrel with that motivation, but the effect of the prohibition has been significantly different from the anticipated outcome. In many counties, the county nursing home is the sole provider of care for the poor elderly and certain handicapped individuals. Many of these individuals could benefit from placement in a more residential setting, but now must occupy Medicaid beds because there is nowhere else for them to go. They contribute to the high occupancy rate of our nursing homes which makes it impossible for hospitals to discharge some patients to our nursing homes, where they could receive less intensive, more suitable, and less costly care. Thus, at both the hospital and nursing home levels of care, greater than necessary costs are being incurred because persons who could be in residential facilities have no available alternative.

Where this regrettable situation prevails, county nursing home administrators have sought to fill the need by developing public residential facilities--often on a campus with the adjacent nursing home. Innovators have attempted to create a true "continuum of care" in which patients could move from one setting to another as their physical needs changed, without disrupting their community-based service delivery. Under such a concept, spouses could remain nearby their loved ones, incentives would exist for rehabilitation of nursing home patients so that they might return to less restrictive environments, and the poor elderly would not be subject to the trauma of discharge into a community which has no place fore them.

Board-and-Care homes in the private sector can augment their income through SSI payments, but since county facilities cannot, pursuit of the development of public residential facilities is discouraged. Net Medicaid savings from placement of patients in more appropriate settings does not benefit public providers under this financing restriction. Rather, the differential must be made up through limited county funding sources--e.g., property tax revenues.

If a portion of the costs of care in a county residential facility could be defrayed by making beneficiaries who are otherwise qualified eligible for SSI, counties would be more likely to extend their services to a continuum of care concept. Elimination of the discrimination against public facilities under these circumstances would produce offsets in excessive hospital stays and inappropriate placements in nursing home Medicaid beds. It would free up the use of beds for those who truly require the

The Honorable George Mitchell
Page 7
March 3, 1987

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[illegible]

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[illegible]

[illegible]

a nursing home attempts to meet the mental health needs of its residents, if it provides trained staff, then its Medicaid funding is jeopardized.

Appended to this testimony is an extended policy paper developed by the National Association of Counties which describes in greater detail the policy implications of the IMD Rule in relation to county nursing homes. We commend it to your attention, because through the complexities of this Rule is woven the clear disincentive to assure patient quality of life through a holistic approach to the treatment needs of the poor, elderly, and handicapped persons served by county health facilities.

The combined impact of these two problems, together with the ongoing financial stresses on county governments, has been to promote the "privatization" of county nursing homes around the country. Our Association receives reports on a continuing basis of the sale of county nursing homes to private providers in places like Michigan, Wisconsin, Georgia, and New Hampshire. Cut off from General Revenue Sharing, faced with property tax limitations in their state constitutions and a taxpayers' revolt in their communities, and saddled with increasing demands for services at a time when Federal assistance is diminishing, counties are looking for ways to unburden themselves of facilities.

But, if "privatization" is the trend of the future, the fear arises that the poor who are now outside the private system of nursing home care will be neglected and unattended. The bottom line is that counties are the "providers of last resort" for these populations and we must not abandon them to an increasingly hostile competitive marketplace.

Modification of the SSI eligibility and IMD Rule will serve to stabilize the financial base of county nursing homes and permit them to serve the health and mental health care needs of those least able to fend for themselves. The changes we urge upon you are humane, equitable, and reflective of our desire to play a constructive role in the evolution of a comprehensive system of care in our nation. We do not ask you to turn the clock back to the days when institutional care was the norm; but, rather, to turn it forward to the day when the frail elderly and the suffering from mental dysfunctions which prevent their complete integration into independent living are given a chance to live near their loved ones, receive necessary rehabilitation, and be freed from the terrors inflicted on mind and body by age, illness, and misfortune. A government of compassion should not be driven by financial concerns alone, but by a genuine concern for the well-being of those entrusted to its care.

The National Association of County Health Facility Administrators would be pleased to work with you and your staff on amendatory language which will address the problems we have identified without adversely affecting our mutual goal of assuring appropriate care delivered in an appropriate setting. Your consideration of this appeal is earnestly solicited.

Sincerely,

Michael B. Shira

Michael B. Shira
President, NACHFA and
Administrator, Newaygo
Medical Care Facility,
Freemont, Michigan

Attachment

NATIONAL
ASSOCIATION
of
COUNTIES

440 First St. NW, Washington, DC 20001
202/393-6226

REPEAL OF THE IMD RULE:

A NACo Position Statement

BACKGROUND

"Before the enactment of the Medicaid program, there was no payment under the Social Security Act on behalf of individuals who were patients in Institutions for the Mentally Diseased (IMDs). The enactment of the original Medicaid legislation in 1965 (Pub. L. 89-97) provided for FFP (Federal Financial Participation) for medical assistance to individuals 65 years of age or older who were patients in IMDs. In 1972, the Medicaid program was expanded (by Pub. L. 92-603) to provide for FFP for inpatient psychiatric hospital services for individuals under age 21, or, under certain circumstances, under age 22.

"Section 1905 (a) provides that FFP is not available for any medical assistance under title XIX for individuals who are in an IMD unless the payments are for inpatient hospital services, SNF services, or ICF services for individuals 65 years of age or older, or for inpatient psychiatric hospital services for individuals under age 22. All IMD benefits are optional; the State must expressly elect to provide coverage in its State plan in order for FFP to be available.

"The statute does not define the term IMD. Medicaid regulations at 42 CFR 435.1009 define an IMD as "an institution that is primarily engaged in providing diagnosis, treatment or care of persons with mental diseases, including medical attention, nursing care and related services." In addition, these regulations provide that an institution is an IMD if its overall character is that of a facility established and maintained primarily for the care and treatment of individuals with mental diseases. . . .

"HCFA (Health Care Financing Administration) uses the following guidelines in establishing the overall character of a facility under the Medicaid statute and regulations. These guidelines are all useful in identifying IMDs although no single guideline will necessarily be determinative in any given case. A final determination of a facility's status rests on whether an evaluation of the information pertaining to the various guidelines establishes that its overall character is that of a facility established and/or maintained primarily for the care and treatment of individuals with mental diseases.

"1. The facility is licensed as a psychiatric facility for the care and treatment of individuals with mental diseases;

"2. The facility advetises or holds itself out as a facility for the care and treatmen of individuals with mental diseases;

"3. The facility is acredited as a psychiatric facility by the JCAH;

"4. The facility specalizes in providing psychiatric/psychological care and treatment. Thismay be ascertained through review of patients' records. It may also be ndicated by the fact that an unusually large proportion of the staff hs specialized psychiatric/psychological training or by the fact tat a large proportion of the patients are receiving psychopharmacolgical drugs;

"5. The facility is uder the jurisdiction of the State's mental health authority;

"6. More than 50 percnt of all the patients in the facility have mental diseases whic require inpatient treatment according to the patients' medical ecords;

"7. A large proportio of the patients in the facility has been transferred from a State ental institution for continuing treatment of their mental disorders

"8. Independent Profesional Review teams report a preponderance of mental illness in the iagnoses of the patients in the facility (42 CFR 456.1);

"9. The average patiet age is significantly lower than that of a typical nursing home;

"10. Part or all of th facility consists of locked wards."

(SOURCE: State Medicaid anual, Part 4--Services, HCFA Transmittal No. 20, September, 1986, evised Material, Sec. 4390, Effective October 1, 1986)

RATIONALE FOR IMD RULE

The care and treatmentof persons in state mental hospitals were traditionally viewedas uniquely state responsibilities. Accepting this view and motivatd by a desire to control costs, Congress excluded FFP under Title IX for persons residing in such hospitals, which were legislatively esignated as Institutions for the Mentally Diseased. Recognizing th special medical needs of the elderly in mental hospitals, an excetion to the exclusion was granted for persons 65 years of age o older. The exclusion was further liberalized in 1972 to alow FFP for persons under age 21 receiving inpatient psychiatric hosital services.

Initially, the IMD rule was applied solely against state mental hospitals, where the liberalization was viewed as a positive step toward more comprehensive coverage under Title XIX. But as the process of deinstitutionalization of the mentally ill accelerated, cost-conscious state mental health authorities began to see enhanced Medicaid funding opportunities through community-based care for mentally ill persons who did not require treatment in the restrictive environment of a state mental hospital. Simply by shifting patients from the hospital to alternative settings, FFP could be obtained for persons formerly ineligible for the Federal Medicaid match.

Reacting to the potential fiscal impact of deinstitutionalization on Medicaid funding, HCFA reassessed its position on the IMD rule in 1979 and looked to alternative settings as possible IMDs. Local nursing homes were prime candidates, since they could easily become mini-State Hospitals for patients "dumped" out of the larger institutions. HCFA targeted Intermediate Care Facilities (ICFs) in four states for closer examination: Illinois, California, Minnesota and Connecticut. Where a nursing home was found to meet the agency's criteria for an institution for the mentally diseased, Medicaid payments were disallowed. The driving rationales for the HCFA position were twofold: 1) Cost containment; and 2) A desire to discourage the use of nursing homes as a new form of institutionalization of the mentally ill.

Not surprisingly, several legal challenges to the Department's regulatory authority arose almost immediately. Most notably, in Connecticut Department of Income Maintenance v. Heckler, 105 S.Ct. 2210 (1985), the Supreme Court held that HHS had the authority, consistent with Congressional intent, to apply the IMD rule against all types of inpatient facilities if they met the criteria established by HCFA. The Court did not rule on the "sufficiency and validity" of the criteria.

An Illinois case framed the question differently. HCFA disallowed $4,261,162 in retroactive payments to 9 Illinois ICFs from October 1, 1976 to September 30, 1978. Illinois appealed the decision. On June 30, 1986, the U. S. District Court for Northern Illinois held that "the evidence assembled under the Guidelines does nothing more than count residents. . .(This) is insufficient to determine the overall character of the institution." It found in part for the State and in part for the Federal Government, insisting that,

> the fact that there are residents with mental diseases present at an ICF is just the beginning of the inquiry. So something more than 50%-plus of persons with a diagnosis of mental disease is necessary. There must be some evidence as to the nature of the treatment provided.

While the courts were busy affirming HHS' right to establish IMD criteria and questioning the appropriateness of the criteria being used, HCFA was in the process of revising its criteria. The agency has basically relied on the International Classification of Diseases (ICD-9-CM) in classifying patients with mental diseases for purposes of the IMD rule. That application has undergone selective modification through the elimination of persons with senility or organic brain syndrome from the census of mentally ill persons. Similarly, mentally retarded persons with autism might be excluded under certain conditions. And non-medical models for the treatment of alcoholism or drug abuse are not counted as inpatient treatment for mental diseases under the IMD rule. Taken together, these interpretations help mitigate the impact of the IMD rule, but do not negate it.

IMPACT ON COUNTIES

Approximately 900 counties nationwide own and operate nursing homes for their residents. Typically, the county-run nursing home serves populations which are underserved elsewhere in the health care system. According to William L. McGowan, President of the Civil Service Employees Association, "80% of all nursing homes are privately operated. By and large, these homes serve their clients competently. The clients of public nursing homes, however, are generally the patients no other home wants. Usually the indigent, long term, and heavy care patients are disproportionately represented in public homes. County nursing homes exist to care for the elderly population that no one else has been able or willing to serve." (NYSAC News, August, 1986, p. 6). Counties are legally liable as the "providers of last resort" for the long term care needs of the older, sicker, and poorer segments of our population.

Deinstitutionalization of the mentally ill has significantly impacted on county nursing homes. Mentally ill persons who are not totally functional on an independent basis in a community, but do not require an intensive or more structured level of care, may find a nursing home a more suitable placement than a group home or satellite apartment. In most cases, an ICF would also be a more congeneal environment than that afforded by a State Hospital. That, in fact, is what has happened in many parts of the country. As the census in state mental hospitals has dropped from 559,000 in 1955 to about 114,000 in 1984, nursing homes have become increasingly a part of the continuum of care for the mentally ill. A portion of the mentally ill residents of county nursing homes are admittedly there because of the lack of other residential community-based alternatives, but others are there because, other things being equal, a nursing home is an appropriate component of a comprehensive service delivery system.

In 1977, nearly 670,000 of the 1.3 million nursing home residents in the United States were classified as chronically mentally ill, although the largest portion of these were characterized as senile. According to Gail E. Toff and Leslie J. Scallet (*State Health Reports: Mental Health, Alcoholism, and Drug Abuse*, July, 1986, p. 2), "Statistics in recent literature indicate that as the number of residents and the length of stays in mental hospitals was reduced, there was a concomitant increase in the use of nursing homes. . . (Between 1950 and 1980) the population in homes for the aged and dependent increased by 381 percent. . . ." AFSCME Councils 40 and 48 report that, "One-quarter of all county nursing home residents are chronically mentally ill, compared to six to ten percent of private sector nursing home residents. The disabled, too, are much more likely to live in a county facility." In Wisconsin, 46% of the nursing home residents with the most severe primary diagnoses (including mental illness) reside in county-operated facilities, even though public homes serve only 26% of the total nursing home population.

Wisconsin may be a special case, because many of its county nursing homes were previously county mental hospitals. But it is not atypical in experiencing a change in the case mix over time. County nursing homes are moving toward the geriatric extremities and more chronically mentally ill young adults. Both populations are high cost groups seriously draining the resources of local governments. In New York, 75-95% of the beds in county homes are Medicaid-funded, compared to private/not-for-profit homes with 20-50% Medicaid beds. Nineteen county homes in Wisconsin have over 90% Medicaid beds. As AFSCME points out, in Wisconsin,

> The state's current Medicaid reimbursement formula does not adequately compensate county homes for their costs of care. Specifically, the Medicaid formula fails to recognize the costs of training and retaining the additional staff required to care for difficult residents. Futhermore, Medicaid reimbursement rates are lower than private pay rates by as much as $40 per day. Private homes simply limit the number of Medicaid residents they accept and make up for Medicaid losses by increasing charges to private pay residents. The deficits of Wisconsin's county nursing homes total approximately $30 million, or 5 percent of all Medicaid spending on nursing homes in the state. (*County Nursing Homes: We Can Afford to Fund Them. We Cannot Afford to Be Without Them*, AFSCME Councils 40 and 48 (Wisconsin), 1986)

With such heavy reliance on Medicaid funding, the threat of disallowance under the IMD rule portends a fatal consequence. County-run homes are marginal operations with very little float in their budgets. Even small dislocations can set up seismic waves of destructive proportions.

Since the initial HCFA action against Connecticut, Illinois, Minnesota, and California, additional audits have challenged payments to ICFs in Washington, Indiana, and Wisconsin. In Indiana, 9 ICFs are in jeopardy of losing $4 million in Federal assistance. Nine of the 46 ICFs in Wisconsin were identified as IMDs. According to Michael W. Berry, Administrator of Dodge County, Wisconsin's Clearview Nursing Home, "We believe that the financial impact of such an audit would, of course, ultimately fall to those counties with facilities identified as IMD's and frankly, none of those counties could stand a 58% cut in its Medical Assistance reimbursement dollars."

County governments are currently financially strapped. They have just lost General Revenue Sharing amounting to $4.6 billion a year. They are often constitutionally limited in the amount of property taxes they can levy. They are faced with strong taxpayer resistance to increased levies. Where the sales tax is a local option alternative, the new Tax Reform legislation has eliminated deductibility and added a new impediment to revenue generation. State and Federal mandates without funding continue to burden local policy-makers. Thus, is it any wonder in the face of implicit and explicit sanctions against county-run nursing homes classified as IMDs, that supervisors and commissioners around the country are looking with increasing favor on the outright sale of public nursing homes or their "privatization" through management contracts with for-profit chains?

The August, 1986 issue of the newsletter of the New York State Association of Counties is replete with articles asking, "Should Counties Be in the Nursing Home Business?"; "Can Counties Afford to Operate Nursing Homes?"; "Public Long Term Care May Be Facing an End;" "Counties Face Financial Crisis in Providing Residential Health Care;" and "Should County Nursing Homes Be Abolished?" The Iowa State Association of Counties, the same month, carried a feature in its magazine entitled, "County Care Facilities: The Trend Toward Privatization." The author of the article, Tricia Fazzini, states, "There seems to have been a rash of privatization among county care facilities (in Iowa) this year. One facility began leasing to a private company in January, at least three facilities began leasing in July, and another will be contracting out to a private nonprofit beginning in October or November. And this is not a complete list by any means."

The fears attending threatened fiscal sanctions under the IMD rule have contributed to growing county governments' interest in privatization. As more and more counties opt to dispose of their nursing homes, the question lingers: Who will serve the needs of those who were formerly the charge of such homes? If they ended up in county facilities because the private sector did not accept them in the first place, does privatization foreshadow their eventual neglect, or will the impact on residents be minimal? Will conversion of public facilities into private nursing homes significantly alter the historic role of such homes or change the nature of the population to be served? The question remains open as to whether the private sector will be willing, or able, in the long run, to perform the social safety net function now assumed by county nursing homes.

IMPACT ON MENTAL HEALTH NEEDS

While the IMD Rule creates financial pressures on counties and may potentially foster a restructuring of the industry, it has even more immediate consequences for nursing home residents with mental health problems. It strongly discourages the provision of mental health services within a nursing home setting by using as a definitional criterion "that an unusually large proportion of the staff has specialized psychiatric/psychological training or that a large proportion of the patients are receiving psychopharmacological drugs." It discourages admissions of mentally ill persons requiring nursing home care by applying a 50% standard against the maximum residential population which can be diagnosed as mentally ill. It discourages consumer information on the quality of services provided by a nursing home, since a home which advertises or "holds itself out" as offering mental health services may be in jeopardy of being classified as an IMD. It provides a disincentive for staff training and development to cope with mental problems of residents, since the presence of a trained staff can be counted as a sign that the home is an IMD.

Even the exclusion of organically-based mental problems and Alzheimer's disease from the IDC assessment tool have not alleviated the problem confronting county nursing homes, since the "overall character" of a home is based on more than simple enumeration of the residents. In fact, the recent court cases have made it clear that treatment is an essential component. In the Illinois case, the Court held that "the fact that there are residents with mental diseases present at an ICF is just the beginning of the inquiry. So something more than 50%-plus of persons with a diagnosis of disease is necessary. There must be some evidence as to the nature of the treatment provided." (Emphasis added). Treatment is the key. If a home does not provide treatment, if it neglects the mental health needs of its residents, it need fear no sanctions. But if it acts responsibily, in the best interests of its residents, and attempts to treat depression or psychosis or other manifestations of mental problems among its resident through specialized services or trained staff, a home faces punitive loss of Medicaid funds.

Conscientious and humane nursing home care should be more than custodial. Where possible, it should be remedial and rehabilitative. But the IMD rule is an impediment to the provision of comprehensive services which promote the physical and mental well being of residents.

Is it cost effective to address only the physical needs of the elderly and the younger mentally ill in nursing homes, while neglecting their mental problems? There is a demonstrable link between physical recovery and mental outlook that suggests that mentally healthy individuals are less likely to require as much medical attention and expenditures as their mentally ill counterparts. The National Mental Health Association's Commission on the Prevention of Mental-Emotional Disabilities notes,

> In old age, the interrelationship of mental and physical health becomes even more critical. Physical illness increases the risk of mental-emotional disability in the elderly. Mental-Emotional disabilities may accompany physical difficulties or result from medications. Chronic physical disease increases the risk of depression. Health care and social service providers working with older people must be informed about and sensitive to the interrelationship of mental and physical health, both in diagnosis and treatment. (The Prevention of Mental-Emotional Disabilities, April, 1986, p. 32.)

Research suggests that mental health counseling can speed recovery from surgery or injury, particularly among the elderly. A psychologically resilient individual is less apt to be accident prone or suffer from minor ailments which might incapacitate a more depressed person.

But far more important than the medical savings that can offset mental therapy costs is the quality of life consideration. What benefit inures to the person whose body is repaired, while the mind is permitted to deteriorate? Can the nursing home resident who experiences the daily horrors of psychosis or depression bless those who merely prolong his mental captivity through physical rehabilitation? If a fire is raging inside a building, applying a fresh coat of paint to the outside is an activity of questionable value. Nursing homes need to serve both the physical and mental/emotional requirements of those in their care. Attention to one aspect of a resident's problems to the detriment of the other is both short-sighted and counter-productive. But that is precisely the way in which the application of the IMD rule drives the system. It penalises nursing homes that seek to treat residents in a holistic manner and elevates quantity of life to a superior position above quality of life. The custodial function can be enhanced through improved medical care, but under the IMD rule, any appreciation of life by a nursing home resident must be an extraneous and serendipitous event. A deliberate strategy to improve the mental health of patients is financially risky business.

If society is to accept its responsibility to assure a minimum standard of quality of life for its elderly, the disabled, and the chonically mentally ill residing in a nursing home setting, the first order of business must be the repeal of the IMD rule. Admittedly, much needs to be done to address the mental health problems of nursing home residents--things like in-take screening, staff training in mental health therapy, strengthening of mental health education in the curricula of schools of gerontology--but all are precedent upon removal of the onerous IMD rule which blocks the way to progress in this area.

The present system creates an impossible catch-22 situation. In order to maintain Title XIX funding, facility administrators are forced to pursue any of several strategies:

1. Refuse to accept patients with mental illness. For persons with nowhere else to go, this approach may be tantamount to their consignment to the streets, where they will be counted among the "homeless." For others, denial of access to nursing home care may force their commitment to a higher level of care in a state institution, thereby defeating the purpose of the deinstitutionalization movement and its premise that people should receive care in the least restrictive environment.

Proponents of the IMD rule point to a study for the National Center for Health Services that concluded that many chronically mentally ill people were inappropriately placed in nursing homes. That study found that 20-60% of the residents in some homes might be receiving more intensive care than necessary. It also found, as innumerable other studies have found, that nursing homes offered little or no significant therapeutic services in mental health and many mental conditions went undiagnosed and untreated. But are such findings an indictment of nursing homes, or are they a reflection of more systemic inadequacies in the design of a community-based continuum of care for the mentally ill? Is the IMD rule the bulwark against abuse its defenders portray, or is it the culprit that perpetuates a shameful neglect of the mental health needs of nursing home residents? Should nursing homes be barred from a constructive role in meeting a community's mental health needs because they are currently prevented from assuming that role in an appropriate way? Local resources are strained already. Existing alternatives cannot cope with the demand. Outpatient clinics are not suitable for everyone who is mentally ill. Some require more structured environments where an array of supervision and services is available. And, for those who are in nursing homes for physical reasons but develop mental health problems, are they to be denied access to needed services on the same basis as others simply because of their domicile?

Nursing homes are not a suitable environment for all, or even most, chronically mentally ill persons. But for some people, under some circumstances, they may be the preferable and least intrusive setting for the delivery of necessary mental health services. County nursing homes, in particular, warrant consideration as potential elements in any comprehensive community-based system of mental health care, because they can extend the range of options available to the poor who are mentally-ill and cannot afford private sector alternatives when outpatient treatment is inappropriate. In the absence of nursing homes, such individuals confront a stark choice among neglect, homelessness, or commitment to a state institution. To the extent that the IMD rule contributes to that shrinkage of options, it discriminates against low-income mentally ill persons.

2. Base admitting diagnoses on something other than mental illness. Assuming there is a public policy stake in reliable information, this approach undermines such an objective. It encourages artificial inflation of exempted categories like Alzheimer's disease, senility, and secondary diagnositic classifications and may result in the serious understatement of the mental health needs of a particular population of patients. Needless to say, it also has a corruptive effect on ethical standards of conduct.

3. Deny admission to youthful patients. This strategy invokes age discrimination and promotes geriatric segregation to meet IMD criterion # 9. At the same time, it may prevent access to needed services to persons under age 65 who are handicapped or otherwise require custodial care in a community-based setting.

4. Restrict or eliminate professional mental health services available to residents. To avoid creating an "overall" character of an IMD (especially in light of the Court's emphasis on treatment as a determining factor), an administrator may feel compelled to avoid hiring staff with mental health training, refrain from providing staff development in the mental health area, and focus care exclusively on physical problems. This approach is a form of penalty-shifting. The facility avoids the IMD penalty, but the price is paid in a penalty of mental anguish needlessly exacted from residents. A less objectionable variation on this theme is for an administrator to attempt to meet the mental health needs of his or her residents through non-medical therapies (AA's, recreational rehabilitation, etc.) or counseling given by untrained staff. Peer group support, pastoral counseling, and similar approaches apparently do not violate the IMD rule against "specialized" staff. Without denigrating such approaches, one must still question a public policy which gives

preference to untrained providers over those with training, to the inexperienced above the experienced, to the amateur before the professional.

5. Address the mental health needs of residents and risk sanction. For the administrator of an ICF who ignores the IMD rule and encourages mental health service delivery within a facility, the potential loss of Medicaid funding can imperil the very existence of the facility. Such an administrator faces a Hobson's choice--either neglect the mental health needs of residents, or risk closure of the facility and the possibility of subjecting residents to transfer trauma or homelessness. The more marginal the financial status of a facility, the more pressing the predicament. And county nursing homes, with their disproportionate share of indigent residents, do not have the financial base adequate to sustain the loss of Medicaid without serious programmatic consequences.

None of the strategies engendered by the IMD rule is acceptable from a public policy perspective. All lead to adverse impacts on patient care. The only positive way out of this negative situation is to repeal the IMD rule and substitute incentives for proper mental health care services in nursing homes in place of the current disincentives.

NACo's Position

The National Association of Counties seeks a legislative remedy to the unfortunate application of the IMD rule to ICFs. Such a remedy should move toward the following elements:

1. Repeal of the IMD rule;

2. Imposition of a mental health component in pre-admission screening of nursing home residents, with assessments made by qualified professionals;

3. Development of individual treatment plans for residents with mental health problems;

4. A requirement that SNF's and ICF's provide mental health services to residents;

5. Adequate reimbursement under Medicaid for mental health services provided in SNF's and ICF's;

6. Provision for monitoring and enforcement of federal standards for mental health services provided in nursing homes.

RESOLUTION

OF THE MEMBERSHIP

NATIONAL ASSOCIATION OF COUNTIES

Adopted in Annual Convention

July, 1986

4L. Resolution on Medicaid Eligibility for Institutions for Mental Diseases (IMD)

WHEREAS, the U.S. Supreme Court in *Connecticut* v. *Heckler*, has upheld denial of Medicaid funds to certain nursing homes caring for former mental hospital patients; and

WHEREAS, under Medicaid law, skilled and intermediate care facilities (ICF) are eligible for federal financial participation while institutions for mental diseases (IMD) facilities primarily involved in providing treatment of persons with mental diseases, are not; and

WHEREAS, today, more chronically mentally ill people are in Medicaid supported nursing homes than in mental hospitals; and

WHEREAS, the ruling will limit the alternative forms of care available to chronically mentally ill persons outside of state hospitals and impose greater burdens on county efforts to deal with this population; and

WHEREAS, terminating Medicaid eligibility for such placements will further shift the costs of caring for such persons to counties; and

WHEREAS, the prohibition on Medicaid eligibility for IMDs will lead to two unintended and undesirable effects:

First, it would encourage the dispersal of the mentally ill among the larger ICF population by ruling out the option that may be much more appropriate for some patients: specialized psychiatrically-oriented ICFs; and

Second, by attaching the risk of Medicaid de-certification where a facility treats a substantial number of mentally ill people, the rule would lead to discrimination in the availability of ICF care to this group of patients; and

WHEREAS, lacking the specialized psychiatrically oriented ICF, the court ruling in favor of HHS will force counties to house the mentally ill in board-and-care facilities, an even less adequate alternative to the ICF.

THEREFORE, BE IT RESOLVED, that the National Association of Counties supports a legislative remedy to the IMD rule that would permit Medicaid eligibility for persons with mental diseases receiving care in SNF and ICF facilities without regard to the IMD criteria of the facilities.

STATEMENT

Submitted By

The National Association of Rehabilitation Facilities
National Easter Seal Society
American Academy of Physical Medicine & Rehabilitation
American Congress on Rehabilitation Medicine

to the

Subcommittee on Health
Senate Finance Committee
U.S. Senate

for the record of

the Hearing on Long-Term Care

February 24, 1987

Mr. Chairman:

This statement is submitted on behalf of the National Association of Rehabilitation Facilities (NARF), the National Easter Seal Society, the American Academy of Physical Medicine and Rehabilitation and the American Congress of Rehabilitation Medicine. NARF is the national voluntary organization of community-based rehabilitation facilities. These facilities serve over 600,000 persons with disabilities annually. Our membership includes freestanding rehabilitation hospitals, rehabilitation units of general hospitals, comprehensive outpatient rehabilitation facilities, home health agencies, skilled nursing facilities, transitional living centers, and vocational and developmental centers. Most, if not all, of our medical membership participate in both the Medicare and the Medicaid programs.

The National Easter Seal Society represents more than 200 state and local societies that collectively serve over 1 million people annually. Nationwide, Easter Seals offers persons with disabilities and others a wide range of community-based rehabilitation services including outpatient medical services, vocational rehabilitation, special education, recreation and related services. A substantial share of these services are provided to Federal program participants, including Medicare and Medicaid beneficiaries.

The American Academy of Physical Medicine and Rehabilitation is composed of about 3,000 certified physicians and residents who practice physical medicine and rehabilitation, known as physiatrists. The American Congress of Rehabilitation Medicine is a professional association of about 3,000 rehabilitation specialists, and includes administrators, practitioners, and physicians interested in rehabilitation medicine who are not physiatrists and others. The professionals of these associations provide most of their services to those suffering from health care catastrophies, i.e., people with severe disabilities and the chronically ill.

The goal of rehabilitation is to restore patients to their optimum level of function and thereby to reduce dependency. Nonetheless, many patients, particularly (but not exclusively) the elderly, require long-term care following or in support of rehabilitation services. Rehabilitation facilities and professionals often face very hard choices in dealing with the needs of their patients because of long-term rehabilitation care requirements and the lack of coverage of such services. The current proposals for catastrophic health care coverage are sadly deficient because they do not address this element of the health care picture.

We are pleased that the Congress and the Committee are examining the issues of catastrophic care. The discussion of catastrophic care today is focusing on what is characterized as acute catastrophic care. Proposals circulated to date only provide relief to Medicare beneficiaries for the deductible and co-insurance costs that can be incurred under Medicare's current coverage. While we certainly applaud efforts on behalf of the Congress and Administration to address this issue we think the Congress should be absolutely clear as to what such proposals will and will not do. The Administration's representations that its proposal will meet the need for coverage of catastrophic illness for the nation's elderly and persons with disabilities is a false promise. If the Congress enacts a proposal to solve this small part of the entire issue it must make it clear that other issues remain to be addressed. Better yet it should address them now. It should also require standards of disclosure relative to Medigap, HMOs and other policies and programs which relate to a catastrophic Medicare proposal. We would urge Congress, as it deliberates upon catastrophic care coverage to consider as a part of defining or measuring catastrophic problems, the severity of the disability involved and its duration.

I. THE PROBLEM

Existing health coverage of an illness or injury requiring care beyond the hospital often does not address all needs for rehabilitation services. While the majority of Americans have some form of health insurance, this coverage is often limited, in terms of maximum dollar expenditures and/or limited in the scope or coverage of services. A patient requiring rehabilitation may exhaust this coverage or the policy may exclude rehabilitation. In either event the patient is faced with the financial responsibility for the services, and if unable to pay, the facility is faced with the grim decision of providing the services free at a reduced rate or not providing them. From a recent survey of our members, we have found that the vast majority, primarily the nonprofit respondents, experience an average 5% charity care and 4% of bad debts out of their total annual budgets, but under increasingly more stringent financial circumstances.

The out-of-pocket costs for the elderly have increased. Medicare covers only 49% of these costs. The average out-of-pocket cost for medical care for the elderly was over $1,000 in 1984. For women over 85, 42% of their income goes to out-of-pocket health costs. Therefore as a result of demographics, medical advances, and the resolution of the need for basic income and access to acute medical care through Social Security and Medicare the dramatic need for long-term care is now being highlighted. Will we tackle it?

A. The Population

As testimony heard by the Committee noted demographic factors have brought the whole issue of the need for long-term care to a critical mass. One of these is simply that people are living longer. Twenty percent of the population will be over 85 years old by the year 2010. While many of these people continue to live in good health until their elderly years a number of them may become disabled, referred to as the disabled elderly. Another group in need of long-term care services are the non-elderly with disabilities who comprise a large percentage of this nation's 36 million people with disabilities. As medical technology has increased the ability to save individuals the issue then becomes what quality of life will these people have. For the young who incur disabilities who then become old, as well as older people with disabilities the need for long-term care occurs long before the age of 65, 75 or 85.

B. Existing Coverage

The Committee has heard extensive testimony about why existing insurance and government coverage does not adequately address either the acute care catastrophic and the long-term rehabilitation needs of many patients. The problems in Medicare, Medicaid, and commercial health insurance highlighted both in previous testimony on catastrophic health insurance and in testimony heard before the Committee on long-term care issues are magnified when focused on a patient needing rehabilitation services. There are glaring gaps in coverage of payment for patients needing a continuum of care of comprehensive rehabilitation services and individuals with disabilities of any age with residual impairments who incur continuing costs for medical, health, and personal care needs.

Most American's have some form of health insurance. However, health insurance may be limited by maximum dollar expenditures and/or the scope of covered services. Medicare and tax deductions help pay for these extraordinary expenses, however, there are 37 million Americans who have no or limited health care insurance. There are also 36 million Americans with disabilities. Of this group, approximately one-third work and receive no public assistance. One-quarter are receiving public assistance but are not working and the balance receive public assistance and 5% of them work, however the nature and extent of their health care coverage is not well known.

A study by the National Center for Health Care Statistics shows that half of those who spend more than $5,000 per year for medical expenses are in institutions. 1.3% of the population accounts for more than 50% of all charges in short stay hospitals, and this pattern holds across all age groups. If data on long stay institutions is added, approximately 2% of the population accounts for over 60% of hospital and institutional care expenses each year. High family costs tend to be concentrated on one family member. Also, high cost illnesses are repetitive and result in repeated hospitalizations, and, these costs began before and continue after the year measured in the studies. Medicare beneficiaries with disabilities use nearly twice as many Medicare services as the elderly and use them more at every expenditure threshold.

A brief study of insurance coverage by NARF showed that coverage of rehabilitation services often depends upon whether a patient is hospitalized. Non-hospital custodial, skilled nursing home care, and/or home health care, are frequently not covered. Medicaid provides some coverage as does Medicare. This limited coverage, which is dependent upon hospital stays, does not address chronic illnesses or disabilities which require intermittent hospitalization, home health, nursing care, or home and community-based rehabilitation services.

Additionally, this study highlighted the problems that exist under commercial health insurance with coverage for rehabilitation services. Last year the Washington Post carried a four part series on the experience of a Virginia family when their 20 year old son was in an automobile accident and suffered severe head injures. This article traced his care from the shock/trauma center through his rehabilitation. The excellent series highlighted all the emotion, time and money which a family experiences when a member suffers a catastrophic illness.

The second article in the series explored the problems the family faced when he was ready for rehabilitation. When the family sought to have him moved to a rehabilitation unit in a local hospital, (which is a NARF member) they discovered that their health care coverage through the Federal Government, a health maintenance organization (HMO), did not cover rehabilitation services. The article notes that the son had been in a trauma center hospital for 78 days before being transferred. According to NARF's recent study the range in length of stay once a patient is referred for outpatient rehabilitation services for a head injury is from 12 to 80 or more days. Again, this is only for the inpatient hospital rehabilitation stay and does not account for the services needed after discharge from the hospital. Such services frequently include continuation of rehabilitation therapies, transitional living programs, transportation, home care needs, vocational and educational counseling.

With respect to this particular case the bills were enormous. The shock/trauma charges alone were over $100,000. The family had never worried about bills before, assuming that the medical insurance through the father's employment covered all possibilities. The family, like many families, had no reason to believe that they would find themselves without coverage. Once the son began to emerge from a coma and qualified for a rehabilitation center, the HMO first stated it would pay none of the cost, estimated at $18,000 per month, for rehabilitation at a rehabilitation center near their home. The family, upon reviewing the benefit booklet which had been supplied, found at the very end of the list of exclusions under "What is Not Covered" an exclusion for "the services of a rehabilitation center." These types of exclusions are not uncommon in commercial insurance coverage and are particularly common with HMOs. However, this particular health plan would cover 100 days a year if the son were in a nursing home as opposed to a rehabilitation center. The family's only other option was to qualify for Medicaid but the only state approved Medicaid facility was 100 miles away.

After a second opinion and strong parental pressure, the HMO agreed to pay for four more weeks of care in a general hospital while the son received speech and physical therapy. It still would not commit to pay for long-term rehabilitation once the son left the hospital. Eventually it agreed to pay for only 60 days of rehabilitation care in the rehabilitation unit of the local hospital.

After intervention by the governor, the rehabilitation center was qualified to treat Medicaid recipients.

When interviewed, the company stated that it tries to predict how many catastrophic bills it may incur and, while it may be willing to absorb "our fair share of cases like this," it did not want to price its product out of the market and suggested that families obtain major medical policies for an additional monthly premium. The Post noted that major medical policies can be difficult to obtain and that most HMOs simply do not offer them.

Almost a year after the injury, the son continued to make progress in the rehabilitation unit and recently went home. He continues to receive a number of therapies. The family is now the major care deliverer.

This care brings into sharp relief the problem of rehabilitation patients, particularly the younger patient. This patient has gone home. Those that can not go home either because they do not receive appropriate rehabilitation services or because of their condition are left with a need for long-term care and generally no one to pay for it.

We submit to you that the first objective in the area of long-term care is to avoid it. We should focus on reducing dependency and allowing people to maintain themselves in their own homes. In many cases rehabilitation is the key to doing this. So in looking at the huge requirement for long-term care we urge this Committee to first look at providing adequate rehabilitation services as a way of avoiding permanent custodial costs.

Existing coverage of rehabilitation has a strong bias toward institutional care. If services are covered, it is generally only when a patient remains in a hospital setting. This results in inappropriate institutionalization and unnecessary care for some patients, and inadequate or unavailable services for others. After hospitalization, a patient is frequently referred for outpatient services, home health care or skilled or intermediate nursing care. When a patient's coverage is exhausted or needs less intense non-covered services, such as non-skilled services, simple custodial care, intermittent therapies, respite care, rehabilitation maintenance or home health aide care, these services are not received. The patient's health may deteriorate, resulting in readmission to a hospital. The cycle beings anew. So do the costs. These problems are becoming increasingly acute as our nation ages and as medical technology saves more people, but leaves them with impairments requiring extensive rehabilitation services.

II. MEDICAL REHABILITATION AND LONG-TERM REHABILITATION PATIENT

Rehabilitation facilities and professionals serve people suffering from major illnesses or the results of accidents. For example, there are over 10,000 people with spinal cord injuries per year and the majority are the result of automobile accidents. There are between 700,000 and 900,000 head injured people per year of which at least 10% (70,000) are considered severely traumatically brain injured. Of these over approximately 50% are the result of automobile accidents. Rehabilitation specialists also treat the elderly who suffer from strokes, arthritis, hip fractures, heart attacks, pulmonary and cardio vascular diseases, neurological and musculoskeletal diseases. These individuals require extensive services both from the time of the injury or illness frequently through outpatient care, home health, adult day health care, residential living care and, in some cases, continued support on a daily basis. These programs have significant costs attached to them. As a result, facility administrators and financial officers face the personal, emotional, and financial trauma that occurs when our existing health care payment system does not help these special patients. These patients include the elderly, as well as non-elderly with disabilities.

Rehabilitation integrates medical and social services. There are over 500 rehabilitation hospitals and units, 100 comprehensive outpatient rehabilitation facilities, 500 rehabilitation agencies and other outpatient providers and numerous home health agencies providing rehabilitation services throughout the country. Most if not all participate in the Medicare program.

The primary function of such facilities is to provide diagnosis and treatment of patients for specified medical conditions both surgical and non-surgical. The average length of stay in a rehabilitation hospital is longer because the objective is restoration of impaired functions which generally follow serious disease or injury. The ultimate objective of rehabilitation is independence. Once a patient is released, many require outpatient and home care services. Rehabilitation can minimize the need for long-term care although some people with disabilities require continuing institutionalization when home and community care is inadequate.

While the emotional benefit of personal independence may not be measured in dollars, psychological, physical and financial independence can. Recent studies of rehabilitation patients who are medically and vocationally rehabilitated show that for every Federal dollar invested the person's earnings increases $10 per hour. Cost studies of stroke rehabilitation also show considerable return on the investment in services. A person who is not rehabilitated, costs $92,736 in 1980 dollars more to support than a rehabilitated patient living at home. The average cost for a stroke rehabilitation program is $8,000 to $11,500 in 1980 dollars. This results in average savings of $81,250 to $84,740, again in 1980 dollars. Rehabilitation should be a cornerstone of a long-term care policy.

III. LONG-TERM CARE NEEDS

The literature on current coverage and the nature of the population shows that there are broad gaps in existing policies when it comes to long-term care needs once the patient leaves the hospital door. Continued care needs are not met through Medicare or Medicaid. Service needs are not met because existing programs and private policies do not recognize nor cover them given the institutional bias that exists. The elderly and people with disabilities want to stay out of institutions. They are happier with their families or on their own. Many such individuals, as shown through the home and community-based waiver program under Medicaid, require only one or two such assistive services in order to remain in their communities and independent.

IV. RECOMMENDATIONS

We recommend that this Committee in considering long-term care issues support programs to move away from the institutional bias for all long-term rehabilitation services and needs. Services that can be delivered by home or through community-based organizations such as rehabilitation facilities, allowing people to live in an independent setting as possible are preferred. To this end, we recommend the following.

A. Medicaid Amendments

With respect to the Medicaid area we recommend:

1. that each patient referred to a nursing home under Medicaid have a rehabilitation evaluation prior to placement in a nursing home. Early rehabilitation can prevent or at a minimum reduce long-term care needs, thereby preventing placement in a nursing home. This may prove to be a great cost savings for the states who are spending close to 45% of their Medicaid dollars for nursing home care.

2. rejection of the Administration's budget proposal to cut and cap Medicaid benefits. These would disproportionately adversely affect all disabled people, elderly and non-elderly.

3. that states be allowed to provide home and community-based waivers without going through the cumbersome administrative waiver process.

4. enactment of the spousal impoverishment proposals and extension of this concept to prevent family impoverishment as well.

B. Coverage

Any bill reported by the Committee should recognize and cover the complete spectrum of the patient's long-term rehabilitation needs. People who do not receive such services deteriorate and and they end up being readmitted to a hospital or a nursing home.

This is a simply waste of time, tax payer or insurance money if, with a little bit of foresight, such a situation can be prevented. Such a continuum of coverage should be in addition to, as opposed to, replacement for existing benefits and not used as a trade-off for or limitation on other benefits. Such services should assume coverage of services offered under Part A and Part B of Medicare as a starting point for the basic package of rehabilitation services.

In addition it should provide for the long-term care needs of rehabilitation patients by expanding services such as outpatient rehabilitation, respite, adult day, home health aide, and psychosocial rehabilitation services. Several bills have been introduced in this session that would move toward coverage of these services which we support. They include H.R. 550, the Medicare Adult Day Care Admendments of 1987. Our members who currently run adult day rehabilitation programs note the cost of such programs is a considerable savings over the cost of a skilled nursing facility ($58,400 average versus $12,500 in New York City); almost a five to one savings. We would also urge the Committee to look into such issues as nutrition, transportation, and housing, particularly for the non-elderly with disabilities. Existing exclusions in commercial insurance for rehabilitation services or rehabilitation sites should be eliminated.

C. Populations

Any final recommendation from the Committee should assure coverage of long-term care needs for all populations including the poor, working poor, unemployed, employed, Medicare and Medicaid beneficiaries.

D. Financing Mechanisms

The major stumbling block in the discussion of how to provide what are almost universally acknowledged as needed services, is the question of how to finance it without creating similar impoverishment for the Federal Government, private insurer, estate, as well as individuals. We understand the Committee will be holding further hearings on this issue and may wish to submit a separate, more detailed statement on financing at that time.

At this time we wish to recommend to the Committee several options to be considered.

The issue of public versus private sector initiatives and therefore funding remains. To what extent should long-term care coverage be provided or mandated through or by the Federal Government, and states or through private health insurance? Should a defined benefits package or mandated benefit package be provided to different sectors based on employment status?

However, several witnesses before the Committee on February 24th said that they originally believed that private health insurance could provide long-term care coverage. They changed their opinion because of the universality of the need for coverage, and recommended services should be provided on a general basis without relying on the private sector. We are pleased to know that private health insurance companies are spending more time trying to develop viable long-term care insurance products that offers a reasonable package of services for a reasonable premium, however many may remain unaffected by such policies because they are unaware or cannot afford them.

If public financing is to be addressed in addition to the discussion on tax incentives and premiums, we would add excise or use taxes. For example, Secretary Bowen in his proposal has suggested that catastrophic health insurance be required of anyone registering a motor vehicle. We would suggest that a true definition of catastrophic health needs and expenses includes long-term care needs and that other sources of financing be examined. Motor vehicle accidents are highly correlated with injuries known to result frequently in long-term care needs such as spinal cord and head injuries. Perhaps there could be an increase in the gasoline tax with a percentage of the tax dedicated to reducing the deficit and another percentage of the tax dedicated to a fund to pay for the long-term rehabilitation needs of those suffering from the results of car accidents.

To the extent Congress takes action, legislatively, to stimulate private long-term care insurance, we would recommend that the legislation provide for the establishment of standards relative to the clear statement of benefits covered and excluded.

A major question is estimating the cost of long-term care before venturing into providing a benefit either by the public or private sectors. The Committee may want to consider examining the concept of the functional status of the patient as a predictor of the patient's care and therefore cost needs. Dr. Stanley Brody in his testimony mentioned several studies that have shown that patients dependent in five or six areas of activities of daily living are those who usually need a full continuum of care. There are a number of tools currently in the field which measure functional status and we would recommend to the Committee if it were to look into this area that it examine them. These organizations are willing to assist in such an effort.

**NATIONAL COMMITTEE TO PRESERVE
SOCIAL SECURITY AND MEDICARE**

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STATEMENT OF

FORMER CONGRESSMAN JAMES ROOSEVELT
CHAIRMAN OF
THE NATIONAL COMMITTEE TO PRESERVE
SOCIAL SECURITY AND MEDICARE

PRESENTED TO

THE SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH

HEARING ON

LONG-TERM CARE OF THE ELDERLY

FEBRUARY 24, 1987

Mr. Chairman, Members of the Committee, my name is James Roosevelt. I am the Chairman of the National Committee to Preserve Social Security and Medicare. I am pleased to present testimony today on behalf of the National Committee's four million members. Long-term care is of vital importance to the members of the National Committee as almost 80 percent of the membership is age 60 and over.

I commend you, Mr. Chairman, for holding these hearings to explore options and directions for the nation's long-term care needs. The costs of long-term care are the truly catastrophic health expenditures for our senior citizens.

Clearly, one of this country's most compelling social goals is to establish a comprehensive policy on long-term care. At this point, we have a fragmented system of federal, state, local and private sector programs. The federal government pays for limited long-term care services through such programs as Medicare, Medicaid, the Older Americans Act, and the Social Services Block Grant to name just a few. Each program has its own set of rules, regulations and eligibility criteria which results in a rigid system with numerous serious service gaps. It is not an exaggeration to conclude that under our current policy, most seniors in need of long-term care services are either too sick, too well, too poor, or too rich to qualify for services.

For example, if you need daily home health care for more than three weeks, you are considered too sick to qualify for such services under Medicare. If you are at home recovering from surgery and you are well enough to get to the doctor's office, you are too well to receive home health services under Medicare. If you are poor and too sick to live independently, you are also too poor and too sick for the nursing home. Due to low reimbursement rates, some nursing homes discriminate against Medicaid patients -- especially if extra care is required. If you have a nest egg, and your spouse enters a nursing home, you will find yourself impoverished before Medicaid kicks in to help support your spouse.

Families provide the largest portion of long-term care in this country, between 80 and 90 percent, and only five percent of noninstitutionalized elderly rely solely on paid, formal sources. A recent House Select Commitee on Aging study of family caregiving found that only after the family has exhausted their physical and financial resources are formal services used. This is important to keep in mind, because it explodes the myth that families dump dependent older Americans and let them fend for themselves in a maze of formal services. The fact that families do take care of their elderly should put to rest some policymakers' fear of overutilization and "the woodwork effect," -- psychologies which work against providing a better system of long-term care.

Nursing home stays, at an annual cost of between $20,000 and $30,000, comprise the bulk of long-term catastrophic cost and are therefore of serious concern. A comprehensive long-term care policy, however, requires a significant expansion of community-based services and a framework that encourages families and individuals to take care of themselves. An expanded network of community-based services will prevent premature institutionalization. This is sometimes preferable on both economic and humane grounds.

While the National Committee supports the expansion of Medicare to pay for nursing home costs, today I would like to emphasize the development of home health and day care services and the alleviation of the problem of spousal impoverishment. These are proposals that Congress can act on immediately.

HOME HEALTH SERVICES

Recently, in an effort to save home health care dollars, there has been a serious tightening of home health services under Medicare. The Health Care Financing Administration (HCFA) claims not to have changed the home health guidelines; however, they are being interpreted much more rigidly than in the past. For example, HCFA insists that for every one dollar in administrative costs, five dollars must be denied in services to Medicare beneficiaries. This type of rule is, at best, arbitrary and, at worst, scandalous. The result is that legitimate services are being denied.

A case in point is in your own state of Maine, Mr. Chairman. During the fall of 1986, the Maine home health agencies reported a sharp increase in denials of claims submitted to Medicare for reimbursement. This trend peaked in the month of

October when the agencies reported that Medicare had denied more than 30 percent of services to their Medicare patients. The home health agencies got the message and stopped accepting Medicare patients.

The big question is, what happens to patients when Medicare denies payment for home health services? Do they pay out-of-pocket for home health services? Do they go without needed services? Or, do they find their way to Medicaid or other reimbursement sources of home health services? The General Accounting Office recently faulted the Department of Health and Human Services for failing to evaluate the effects of stronger controls on unmet patient needs.

Let me illustrate by two case examples, both from residents of Maine, the types of problems people who are denied services are experiencing.

*A 92-year old man, living alone in a trailer, wrote the following to his Representative in Congress:

> Medicare has just taken away the regular visits made to me by an RN once a month and a Home Health Aide 3 times per week. Without the help of a nurse to cut my toenails and take care of the sores I sometimes get on my legs, I don't know what I'd do. I have diabetes and she checks my blood sugars and gets my insulin increased or decreased if it needs to be. I can't get along living alone in my trailer without the help of the girls that bathe me. Me feet swell so badly and I need help getting my stockings on and off. ...I might have to go to a nursing home and I don't want to do that. I've managed this long and I feel I can manage a little longer with the help of Medicare.

The reason cited by Medicare for denying services to this man was that skilled nursing care was not required. (I understand that it took intervention from his Representative in Congress to get services restored).

*A 71-year South Portland woman living alone was denied home health services one week after rectal surgery. The patient was able to walk to the bathroom but was otherwise confined to bed. Her condition weakened to the point where she needed to enter a nursing home. She still needed home health services after release from a seven-day stay in the nursing home, yet Medicare denied services on the grounds that "the nursing services ... required could have been safely and effectively rendered by a nonmedical person. Thus, they cannot be considered skilled nursing services regardless of who actually performs or supervises the services."

Mr. Chairman, it is appalling to think that this woman, living by herself, would have to ask a non-medical person to provide the needed care after rectal surgery -- especially considering the delicate nature and location of her wound. A program which is so rigid that it does not take into consideration the overall situation of the individual cannot be an effective program.

The National Committee fails to see the logic in squeezing reimbursement of home health services at a time when the prospective payment system results in patients being released from hospitals earlier. If an individual needs medical care in the home, Medicare should pay for it and stop making arbitrary restrictions. The National Committee recommends that Congress eliminate barriers such as the "homebound" and "intermittent" criteria and expand the interpretation of which conditions require "skilled nursing care" in the home. The National Committee also recommends that the arbitrary five to one rule be eliminated.

ADULT DAY CARE

The second service element in the long-term care spectrum that I urge the Committee to look at is adult day care. Adult day care is a primary example of custodial care in the community. It includes a range of health and social services to chronically ill or disabled individuals in a group setting. It serves several purposes: an elderly person feels less lonely and isolated; it postpones or curbs the need for institutionalization; it provides relief to caregivers from full-time caregiving; and, it enables the caregiver to hold a job outside the home.

Despite the rapid growth in adult day care in recent years, still only about 10,000 to 15,000 disabled adults are served in approximately 1,000 facilities across the country. According to a study published by the National Council on the Aging, day care serves an estimated 2,000 to 3,000 adults who are victims of Alzheimer's disease or other mental disorders. Considering that there are an estimated two and a half million individuals with Alzheimer's disease who could potentially benefit from adult day care, there is clearly a need for more adult day care services. Experts have found that because of their special need, it is beneficial for Alzheimer's victims to have centers that serve strictly these individuals. One such example is the Alzheimer Project in Gardner, Maine. This important model project, which received your full support, Mr. Chairman, offers boarding facilities as well as day care for Alzheimer's victims. Congress should encourage this type of project because families of Alzheimer's victims are desperate to find services for their dependents.

This Committee must consider the critical need for respite care. Family caregivers need support services, such as day care. Only with occasional relief, can caregivers continue their important work without themselves becoming exhausted and incapacitated.

The National Committee recommends increased funding under the Older Americans Act to pay for adult day care. The National Committee also recommends that Congress consider a supplement to a Social Security benefit when an individual is so severely disabled as to require constant care. This benefit would help to pay for day care or home care services or permit a spouse or other relative to quit a job to take care of the severely disabled individual, without excessive financial hardship. Eventually, however, adult day care should be covered under Medicare.

SPOUSAL IMPOVERISHMENT

The third area of deep concern is the serious flaw in the Medicaid program which results in spousal impoverishment when one spouse is institutionalized. Mr. Chairman, I am delighted to learn that you are addressing this problem in the "Medicaid Community Spouse Protection Act of 1987." Medicaid will not pay for a nursing home stay until the institutionalized person has spent almost all of his or her assets, including, in some states, a lien on a home. The non-institutionalized spouse must exhaust her share of the assets as well. A couple can make the best plans by saving and investing in the hopes of remaining independent in old age. Yet, few realize how fragile such savings are. When faced with the costs of institutionalization of more than $20,000 a year, it does not take long to use up the average retirement nest egg. It is frequently hard for the non-institutionalized spouse, usually a wife, to make ends meet during or after the institutionalization of her spouse. Often she is forced to seek public assistance.

The National Committee recently received a letter from a member describing the guilt he and his mother felt over their sense of relief when the institutionalized father died before the funds were exhausted:

> ... he had to be put in a nursing home - at a cost to my mother of about $2,400 per month. And neither Medicare nor Medicaid could help because my parents had a nest-egg. The law is without pity... Had my father lived for just two more years in the nursing home, my mother would have had to spend the rest of her life in poverty. But God called Pop to his eternal rest in one year, rather than two. My mother and I can never forget the terrible feeling of relief we had when Pop died. We can only live with it in shame. We loved him.

The National Committee recommends that at least half of a couple's assets and income be reserved for the non-institutionalized spouse. Such a policy would help to preserve the independence of one of the most vulnerable sections of society, elderly widows.

Last, I want to point out that in looking to improve our system of long-term care in this country, the many gaps in services and in the financing of these services must be closed. A single funding source would allow for more flexibility. To avoid gaps in the delivery of services, central points of entry and assessment of service needs are essential. The maze of programs and services is confusing and overwhelming for the average person looking for support services. It makes sense to have one central location to which to turn. The one-stop or "gateway" agency would be responsible for hooking up the person with the right services and for coordinating the various services. This type of "gateway" approach would also help prevent premature institutionalization by screening individuals who could be served in the community with the help of formal services.

I urge you to consider this one-stop approach in any comprehensive long-term care legislation that you may be examining.

In conclusion, let me state that the National Committee supports proposals to expand Medicare to cover acute catastrophic expenses. However, we urge that Congress consider the long-term care catastrophic expenses of prescription drugs, home health services and long-term care institutionalization as well. With Medicare paying less than one half of the health costs of older Americans, there is clearly a compelling need for further protection.

THANK YOU.

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